Leprosy In Norway: An Interplay of Research and Public Health Work¹

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INTRODUCTION

The history of leprosy in Norway is characterized by achievements reached through mutual fertilization and cooperation between research and public health work. Of the milestones that mark the paths of the story, one dates back to 1849, when a clinical research center for leprosy was established with the opening of a special leprosy hospital, Lungegaard Hospital, in Bergen. This hospital gave the outstanding Norwegian physician D. C. Danielssen (1815-1894) the opportunity of continuing extensive research into the clinical and pathologic aspects of the disease. Soon publications from his hand made a great impact on professional as well public opinion with respect to the nature of leprosy.

A better understanding of the disease led to a desire to quantify the problem. National patient censuses were conducted. These were the forerunners of the foundation in 1856 of The National Leprosy Registry, which, like the clinical research center, was located in Bergen. The material of the registry provided a unique opportunity for epidemiologic research and was essential in the control of the disease. The foundation of a clinical research center and a national patient registry paved the ground for another highlight of Norwegian leprosy work: Armauer Hansen's (1841-1912) discovery of the leprosy bacillus in 1873.

These accomplishments were possible because the authorities of the period not only had the willingness but also the ability to embark on the solution of a major public health problem. Of utmost importance was the trust the government placed in the

results of research activities. This made it possible, in 1877 and 1885, to pass laws providing a legal basis for the measures considered to be necessary for the control of the disease.

RECOGNITION OF A PUBLIC HEALTH PROBLEM

When leprosy first appeared in Norway is not known with certainty. Its presence about 800-1000 A.D. was undoubtedly linked with the raids of the Vikings, particularly to the British Isles (39, p 53; 41, p 106). There, as in the rest of Western Europe, leprosy was a common disease at the time of the Crusades. Towards the end of the Middle Ages its frequency declined considerably and the disease almost disappeared in the northern part of the continent. On the Scandinavian peninsula, however, a new wave of the disease arose, peaking in Norway about 1860. Norwegian leprosy research, and the work that led to control and prevention of the disease, was started in conjunction with this last wave.

Prior to the 1820's the Norwegian authorities, apparently did not regard leprosy as a serious health problem. The decades that followed saw major changes in attitudes towards the disease. This took place in the wake of the Napoleonic war which brought problems to the Norwegian economy. The whole population was affected by the economic problems, but especially the underprivileged classes, among which sufferers from leprosy formed a small but significant group. In ordinary times the life of these patients was hard enough, but in times of crisis their position became almost unbearable. This situation was first brought to the attention of the authorities in a report written by the pastor of St. Jørgen's Hospital in Bergen, J. E. Welhaven (1775-1828) (48). The report was published in a medical journal in 1816,

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and gave the impression that this leprosarium functioned as a graveyard for the living.

St. Jørgen's Hospital, which was the only large leprosy hospital in Norway at that time, has a long history (27, p 24). It appears to have been founded in conjunction with a monastery in the beginning of the 15th century, and was a purpose-built leprosarium. Patients with other diseases were later admitted to St. Jørgen's Hospital, but from about the middle of the 17th century it functioned solely as a regional leprosy hospital for the western parts of Norway. The disease was especially prevalent in these parts of the country. St. Jørgen's Hospital, therefore, came to play a central role in the treatment of leprosy patients in earlier days. The hospital was ravaged by fire on several occasions and was rebuilt. The last major reconstruction took place in 1754, the hospital then housing about 150 patients.

The growing interest in the problem of leprosy stemmed to some extent from the Norwegian Declaration of Independence of 1814, and the Constitution framed at that time. These events gave a great boost to Norwegian nationalism. Everything that was specifically Norwegian came into the limelight, and it was in the villages that the truly Norwegian elements—and leprosy—were found. The increasing interest shown in the rural population led to a closer knowledge of the problems of the peasantry.

Greater knowledge of social problems led to a concern in public health, both on the part of the authorities and of the medical profession. This concern was not confined to the simple registration of the problems; there was a strong feeling that the problems could and should be solved. The great medical challenge of this time was the acute epidemic diseases. However, interest was also shown in the more general problems of public health, an interest which in Norway was brilliantly demonstrated in Eilert Sundt's (1817-1875) major demographic and sociological works on the lower social classes (1).

Thus, the fact that leprosy was prevalent in large regions of the country was brought to public attention. It was realized that leprosy was a disease which in certain districts attacked large groups of the population, and thus was a mass phenomenon of much the same magnitude as the epidemic diseases. Further, it became clear that leprosy was a chronic disease with the most serious social consequences for those afflicted.

The dimension of the public health problems was unknown, however, and a physician, J. J. Hjort (1798-1873) was engaged by the authorities in 1832 to travel about the various districts of the country, and report on the extent and gravity of the leprosy problem. Hjort was also to express his views on whether or not anything could be done to improve the conditions of sufferers from leprosy. In his report he was unable to quantify the leprosy problem with any degree of certainty, but was of the opinion that there was a great need for hospital beds, both for treatment and care (22, p 11).

In 1836, in order to obtain more definite information about the magnitude of the problem, the authorities made a census of all sufferers from leprosy. The work was done by the parish ministers, and 659 patients were found, corresponding to a prevalence of 5 per 10,000. Registration methods were inaccurate, however, and it was assumed that the real number was far greater.

The seriousness of the leprosy problem documented through the leper census, the report by J. J. Hjort, and not least by the fact that nothing had been done to improve the living conditions of the patients in St. Jørgen's Hospital led to a proposal in Stortinget, the Norwegian parliament, that the state should build new leprosy hospitals in those parts of the country in which the disease was prevalent. The result of this proposal from the members representing Bergen in parliament was the appointment of a government committee to report on the leprosy problem. Hjort, who was a member of the committee, was given the opportunity of going abroad to study the disease, and the measures taken against it. The report published by the committee in 1838 proposed that four leprosy nursing hospitals be established (22, p 15).

THE FOUNDATION OF A RESEARCH HOSPITAL

Before the report of the committee was presented to parliament, the authorities were anxious to have more definite knowledge of the disease itself. Effective methods in the struggle against leprosy would require knowledge of the etiology, clinical symptoms and epidemiology of the disease. C. W. Boeck (1805-1875), at the time a medical officer for a mining company, was awarded a scholarship permitting him to study the disease in other European countries. At the same time D. C. Danielssen, who in 1839 was engaged as a physician at St. Jørgen's Hospital in Bergen, was requested to continue the studies he had already begun on the clinical and pathologic manifestations of the disease. The results of their work were published in 1842, and on this basis parliament decided, later in the same year, to found a research hospital in Bergen for leprosy (9, p IV; 22, p 17). The hospital, which accommodated about 90 patients, was completed in 1849, and Danielssen became its first Chief Physician.

The foundation of this hospital in Bergen represented the first major financial commitment made by the government in the field of leprosy, and it is worthy of note that the main purpose of the institution was research. Although this aim was not explicitly stated in the resolution passed by parliament, which referred to the hospital as a "curative institution" (22, p 17), it became clear, once it was in operation, that its main purpose was to evolve effective methods of treatment (36).

The reason why Lungegaard Hospital was made a research center must be sought in the need felt by the authorities for more exact knowledge of the disease; a need that had called for a leprosy census, the appointment of a special committee and the initiation of research work. This work, particularly that done by Danielssen and Boeck, drew further attention to the opportunities which existed for making Bergen into a center for leprosy research.

In 1847 Danielssen and Boeck published

a monograph later printed in a prizewinning French edition (9). The monograph is divided into two main sections. The first gives a detailed and critical account of former literature on leprosy, the second presents the authors' own results, with documentation and discussion. Here the clinical signs and morbid anatomy of the disease were discussed in detail; the polar forms were characterized and the epidemiological observations were described and commented upon. Leprosy was considered to be caused by several factors.

In an attempt to quantify the relative importance of these factors it was stated that the disease was usually hereditary, but that one-eighth of the cases were due to so-called incidental factors, such as hard toil and bad living conditions. The book was of fundamental importance for subsequent leprosy research, and the authors soon became recognized authorities on the subject. R. Virchow (1821-1902) stated in 1864 that earlier works were of little scientific interest compared with this monograph (45, p 563).

It was in the same research center in Bergen that Armauer Hansen later carred out the work that led to the discovery of the leprosy bacillus. Together with C. Looft (1863-1943) Armauer Hansen wrote a monograph: "Leprosy in its Clinical and Pathological Aspects" (20), which in an excellent manner carried further the traditions founded by Danielssen and Boeck. The work is an extremely valuable scientific dissertation, even when assessed by to-day's knowledge of the disease (47).

FORMULATION OF A CONTROL PROGRAM

Although a research hospital had been established, and successful research programs completed, no measures had been taken to solve the public health problem represented by the disease. There was still uncertainty with regard to the magnitude of the problem. A new leprosy census was therefore conducted in 1845 in conjunction with an ordinary population census. It was found that there were 1,123 patients, corresponding to a prevalence of 8 per 10,000; a considerable increase since the first census

in 1836. Further, leprosy was registered in parts of the country which had formerly been free of the disease, that is, in central districts of eastern Norway. Again in 1845 inaccuracies were demonstrated in the census, and it was assumed that the real number was higher than that indicated (7).

The permanent Medical Committee of the Ministry was asked to propose practical measures against the disease. After a very thorough discussion (36), the Committee recommended the execution of the earlier plans for the foundation of nursing institutions. These plans were based on the assumption that the disease was hereditary, and that sexual isolation of the patients in these institutions would prevent them from passing on the disease. This view on etiology led the committee to propose that all sufferers from leprosy and their descendants "in the first and the second degree" should be forbidden by law to marry. A ban on marriage would necessitate a detailed knowledge of all patients and their families, throughout the whole country. The committee therefore proposed that a patient registry should be established for leprosy. Such a registry would require extensive administrative work, and it was proposed that posts should be established for medical officers to lead the leprosy control program.

The committee also commented on the question of the justification of a research hospital. It had been claimed by some that leprosy was incurable, and that the health authorities should simply establish and run nursing institutions rather than research hospitals. The committee protested against this view, and pointed out that there was a clear need for further scientific studies.

The report of the Medical Committee led to wide debate, particularly on the question of forbidding sufferers from leprosy to marry, and the proposal to this effect was finally rejected by parliament. To obtain further information on the need for control measures the health authorities made a third leprosy census in 1852. This time the census was conducted by the District Health Officers, and a total of 1,782 patients were registered (7), a prevalence of 11 per 10,000. The census showed

a continued increase in the number of patients, and this led to a forced implementation of control measures. For central coordination and administration of the work, the post of Chief Medical Officer for Leprosy was established in 1854. Control measures on the local level were entrusted to the District Health Officers, assisted by the local Boards of Health. These Boards were established in 1856 in the districts where leprosy was found, and were made up of members of the District Councils, who had detailed knowledge of the conditions in the district.

Another important step in the control program was the construction of nursing institutions. In the course of the years 1854-1861 hospitals housing a total of 680 patients were built. In addition to the 250 beds in St. Jørgen's Hospital and Lungegaard Hospital, this represented a considerable capacity, especially in view of the fact that there were never more than 3000 sufferers from leprosy in the country at any one time.

THE FOUNDATION OF A NATIONAL LEPROSY REGISTRY

O. G. Høegh (1814-1863) became in 1854 the first Chief Medical Officer for Leprosy. He realized that practical control measures would have to be based on current information on each patient, and that there was a need for the establishment of a central patient registry (3, p 4). A registry would make it possible to assemble all current information in a way that would show where control measures were most in need, and would permit an evaluation of the control program. Høegh also appreciated that a registry would provide a basis for fruitful co-operation between practical public health work and research, particularly with respect to epidemiologic studies on the etiology of the disease.

The Leprosy Registry was established by the Royal Decree of 30 July 1856. It was founded for the the dual purpose of research and the control of the disease, and is probably the first national patient registry ever to be established (29).

The local registration work was carried

out by the District Health Officers with the assistance of the parish ministers and members of the local Board of Health. New cases of leprosy were notified annually to the central registry in Bergen. The District Health Officers also supervised the leprosy patients and decided when they needed hospitalization.

Local registration work was supervised very conscientiously by the Chief Medical Officer for Leprosy, who spent long periods of the year traveling around the districts concerned. During these trips the Chief Medical Officer saw most of the patients himself, and assisted the District Health Officers with diagnostic problems.

RESEARCH ON ETIOLOGY AND THE DISCOVERY OF THE LEPROSY BACILLUS

Although the leprosy control program envisaged by the health authorities was based on the view that leprosy was hereditary, there was no general agreement on the question of the cause of the disease. In the period of 1850-1870, the leprosy question attracted considerable attention in professional circles. In 1857, for instance, it was the subject of a protracted discussion by the Medical Society of Oslo (10). Etiology and control measures were the two main themes of the debate.

Most doctors concurred in the conclusion of Danielssen and Boeck that leprosy was a hereditary disease, but spokesmen for other views were also heard. A District Health Officer, H. Holmsen (1812-1888), stated in a symposium conducted by the Ministry of Health that leprosy, in his opinion, was caused by miasmas (24). J. J. Hjort maintained that leprosy was a degenerative condition with various causal factors, most often being a result of harsh physical conditions of life. The first to present results of analyses of a large body of observations on the question of etiology was O. G. Høegh (3). He held that the data from the Leprosy Registry gave support to the hypothesis that leprosy was an infectious disease. Although opinions varied as to the causal factors of the disease, there was general agreement on the need for further scientific investigations. Funds were established to

support leprosy research, and physicians were engaged for the work.

of these, Bidenkap J. L. (1828-1892), carried out extensive epidemiologic studies (4,5). He did not consider leprosy to be a nosological entity. Some cases were assumed to be due to contagion, the majority were assumed to have a composite etiological background, often with a

major hereditary component.

To clarify the etiology of the disease was considered so important that extensive and elaborate epidemiological migration studies were carried out. The extent of the disease was investigated among Norwegian emigrants to the U.S.A. (2, 6, 23, 33). The results of these studies, however, did not contribute to the clarification of the question of etiology.

Leprosy was also attracting considerable attention in other countries at this time, and some publications made a great impact on the discussion of etiology in Norway. In 1867 a report was published by the Royal College of Physicians, London, based on replies sent in by about 250 physicians in all the colonies of Great Britain. These physicians had been asked to answer 17 questions, with the aim of clarifying the etiology of the disease. The replies, however, were highly contradictory (34). Greater importance attached to C. L. Drognat-Landre's work of 1869: "De la contagion, seule cause de la propagation de la lèpre" (11). This study, which was based on material from Dutch Guiana, gave substantial support to the theory of contagion. It seems that this book had a decisive influence on the young Norwegian physician G. H. Armauer Hansen and on his view on the etiology of the disease. In 1872 he wrote that it was this book which drew his attention to the lack of adequate studies in Norway on the question of the communicability of leprosy (14, p 21). This statement explains in part how Armauer Hansen arrived at his working hypothesis.

Armauer Hansen graduated as a medical doctor from the University of Oslo in 1866 and was an intern at the University Hospital for about a year. After a few months as a physician in the Lofoten islands, a fishing district in the north, Armauer Hansen started his studies of leprosy in 1868. He worked at Bergen's active research center, Lungegaard Hospital, and this must have exerted a considerable influence on his line of development. Armauer Hansen was undoubtdly also inspired by the general debate on contagion that was being carried on in this period, and by excellent epidemiologic works published in the 1860's, all tending to the conclusion that certain diseases were caused by contagious matter transmitted from individual to individual (25.26).

Technological developments in the early 19th century brought with them improvements in the microscope, and made it possible to study microorganisms. During the first six decades of the century a number of newly discovered fungi and parasites were considered to be the cause of various diseases. The first microorganism proved to be pathogenic in humans was the anthrax bacillus. In 1869, C. Davaine (1812-1882), following the rules drawn up by J. Henle (1809-1885), was able to prove that this bacillus was the causative agent of anthrax (43).

Research on microorganisms also attracted attention in Norway at this time (44, 46), and scientific studies were taken up. E. F. H. Winge (1827-1897) and H. Heiberg (1837-1897) found in 1869 chain-like threads on the heart valves of a patient who died of sepsis (49). These threads were considered to be pathogenic microorganisms, and were later identified as streptococci. Armauer Hansen was acquainted with these scientific works when he began his studies on leprosy (28).

Armauer Hansen's first publication, in 1869, presented a general pathologic description of leprosy (12). In his next paper he gave a detailed account of the pathology of the different organs (13). His observations constituted pioneer work in this field and were, in addition, a valuable corrective to Danielssen's studies, in which certain tuberculous manifestations in organs were assumed to be leprous. Armauer Hansen concluded that leprosy was a specific disease, representing a nosological entity with a clearly definable etiology, and not simply a degenerative condition resulting from various causes.

It was in 1870 that Armauer Hansen first discussed the etiology of the disease against this background (13). He pointed out that most findings seemed to indicate that leprosy was a chronic infectious disease. It seems doubtful whether the concept "chronic infectious disease" had the same meaning then as to-day. Nevertheless, it is quite clear that he assumed that leprosy was communicated from person to person by infectious matter. He realized, however, that he was unable to prove this hypothesis. In his next publication he gave a critical evaluation of the discussion being carried on in professional circles (14). E. F. Lochmann (1820-1891), who supported the hypothesis of contagion, had claimed that certain of Hansen's pathologic findings proved that the disease was contagious (34). Hansen pointed out that this conclusion was unjustified, and attempted instead to support the hypothesis by means of analogies. Leprosy was conceived of as being analogous to syphilis, a disease generally accepted as contagious. It was, however, unlike tuberculosis, which Hansen, like all authorities at that time, claimed was hereditary.

In the work published in 1874 (15), which was printed in a somewhat abbreviated form in an English journal the following year (16), Armauer Hansen mentioned for the first time his discovery of bacterialike formations in leprous nodes. The work is a fairly long report, mainly of epidemiologic nature. He had obtained his extensive material partly from investigations in the field, partly from the Leprosy Registry. The conclusion of his epidemiological analysis was that leprosy most probably was contagious. The main argument for this assumption was the information from the Leprosy Registry which showed that the number of new cases of the disease declined most quickly in districts in which isolation of patients in hospitals had been most consistently enforced. Towards the end of the publication Armauer Hansen mentioned that he had observed bacterialike rods, and indicated that they resembled the illustrations of bacteria earlier published by E. Klebs (1834-1913) (15). He went on to state that he could not prove

that these rods represented the causative agent of leprosy. This reservation must be seen as the expression of a general critical attitude. It cannot be taken as ignorance with regard to the significance of the findings which were discussed in detail. Although the final proof has been difficult to establish, even up to the present day, it soon became generally accepted that leprosy was a contagious disease, and was caused by the microorganism demonstrated by Armauer Hansen.

The discovery of the leprosy bacillus was another example of the interplay between research and practical leprosy work in Norway. On the one hand, Armauer Hansen based the hypothesis of contagion on data obtained in the course of practical public health work, that is, from the Leprosy Registry. On the other hand, the recognition of leprosy as a contagious disease, and the discovery of the leprosy bacillus, made a great impact on public health work.

LEGISLATION FOR THE CONTROL OF THE DISEASE

In 1875 Armauer Hansen was appointed to the post of Chief Medical Officer for Leprosy. He took over the post from T. J. Løberg (1819-1882) who had held it since 1858. Armauer Hansen claimed that the available evidence, indicated that the control program should be altered to permit the isolation of the most contagious patients. He used information from the Leprosy Registry to show the necessity of such measures. In 1875 he calculated, by extrapolation, the number of cases to be expected in the various districts in the years 1885 and 1915 (29). The prevalence of the disease would gradually decrease, but not as quickly as desirable (17). Isolation was therefore necessary. It was considered that isolation in the patient's own home was in many cases illusory, and it was obvious that a large number of patients would have to be hospitalized. Hitherto admission to hospital had been voluntary. It was usually patients in very poor general condition who were admitted to hospitals, and it had rarely been difficult to persuade these to give their consent. Now, however, it was found to be necessary to

isolate patients whose general physical condition was relatively good. These patients were inclined to consider the measures as unnecessary and unjust, and often refused to enter hospital. It was obvious that spe-

cial legislation was required.

In 1877 the "Act for the Maintenance of Poor Lepers, etc." (30) was passed. This Act prohibited the boarding-out system as far as leprosy patients were concerned. The boarding-out system was a collective system for the support of the indigent of the parish, under which those who could not support themselves were sent to different farms in succession. Hereafter leprosy patients who were unable to maintain themselves had to be hospitalized. In 1885 the legislation was considerably extended by the "Act on the Seclusion of Lepers, etc." (31). This Act provided that all patients must be either isolated in separate rooms in their homes, or admitted to hospital, if necessary with the help of the police.

The Act of 1877 was passed without much opposition. The bill proposed in 1885, however, gave rise to an extensive debate in professional circles (17, 19, 50), although it was claimed that the bill simply represented a legitimate recognition of the practice that had earlier been followed (21). Isolation was viewed as an unnecessary burden which should not be inflicted on persons who were already so sorely tried. It was claimed that the disease could be eradicated without the use of isolation. However, Armauer Hansen was able to show, on the basis of data from the Leprosy Registry, that the number of new cases had diminished most rapidly in the districts in which hospitalization had been most consistently enforced (18). This argument carried considerable weight in the debate on the proposed bill.

As a result of Armauer Hansen's work it became generally accepted that leprosy was a contagious disease. Although this found expression in Norwegian legislation it was still assumed that the danger of contagion was very slight and that intimate contact over a long period was necessary for the communication of the disease. The isolation enforced in Norway was therefore relatively mild. Hospital patients had full

freedom of movement, but had to spend the night in hospital (38).

THE NORWEGIAN CONTROL PROGRAM AS AN INTERNATIONAL PROTOTYPE

The first official to visit Norway to study leprosy control was the English Surgeon Major H. V. Carter (1831-1897), who in 1873 was sent by the British Government from India. He found the Norwegian control program very convincing, and wanted to introduce parts of it in India (**). In 1890 Roose (***) published a work entitled "Leprosy and its prevention as illustrated by Norwegian experience," in which he gave an account of Norwegian leprosy work, and emphasized the importance of isolating patients to "restrain the spread of leprosy by infection."

Eventually, the Norwegian leprosy control program won international recognition, a recognition which was expressed at the First International Leprosy Congress, held in Berlin in 1897. The congress passed the following resolution: "Das System der obligatorischen Anmeldung, Überwachung und der Isolation, wie es in Norwegen durchgeführt ist, ist in allen Nationen mit autonomen Gemeinden und hinlänglicher Zahl der Ärzte zu empfehlen" (40).

EPILOGUE

In 1912, on the death of Armauer Hansen, the post of Chief Medical Officer for Leprosy was taken over by H. P. Lie (1862-1945). Lie continued the work in the tradition of co-operation established between research and practical public health work. His main scientific work was his doctoral thesis, published in 1904: "Lepra im Rückenmark und de peripheren Nerven," in which it was demonstrated that the morphologic alterations in the central nervous system are of a nonspecific degenerative nature (32). Lie was also interested in the epidemiology of the disease, and continued to lay great weight on the Leprosy Registry, both for scientific purposes and for patient control. Through the International Leprosy Association, of which he was one of the founders, Lie also took part in international leprosy work.

In 1935 R. S. Melsom (1899-) was appointed to the post of Chief Medical Officer, in which he continued until 1957, when the number of patients had fallen to seven. Melsom considered that it was no longer necessary to have a Chief Medical Officer for the disease, and the post was therefore abolished in this year. Melsom was particularly interested in the epidemiology of recent cases, where it often was extremely difficult to trace the path of contagion (37).

Melsom, during his period of office, followed the guide lines previously established in the registration work. The Leprosy Registry therefore holds material collected continuously over a period of more than one hundred years. Compared to other materials available on the epidemiology of leprosy this is quite a long period of observation (35). The material of the Norwegian Leprosy Registry represents therefore a unique source for the study of the epidemiology of the disease. Today this material is being worked up according to modern data processing technics, and an old tradition of research is being continued (29).

SUMMARY

Leprosy was recognized as a major public health problem in Norway in the last century. The remarkable decline of the disease that followed is for the greater part attributable to the interplay of research and public health work in the fight against the disease. In 1847 Danielssen and Boeck published a great monograph which provided the health authorities with a scientific basis for the control program to be implemented. The research work was continued at a clinical research center for leprosy established in 1849. The National Leprosy Registry, founded in 1856, was essential in the control of the disease and provided unique opportunities for epidemiological research, which in 1873 led to the discovery by Armauer Hansen of the leprosy bacillus. This discovery subsequently formed the basis for the legislative actions taken in 1877 and 1885 for the control of the disease.

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