



Leprosy: Social implications from antiquity to the present

Andrzej Grzybowski, MD, PhD, MBA^{a,b,*}, Jarosław Sak, MD, PhD^c,
Jakub Pawlikowski, MD, PhD^{c,d}, Małgorzata Nita, MD, PhD^e

^aDepartment of Ophthalmology, Poznań City Hospital, ul. Szwajcarska 3, 61-285 Poznań, Poland

^bMedical Faculty, University of Warmia and Mazury, Olsztyn, Poland

^cDepartment of Ethics and Human Philosophy, Medical University of Lublin, 20-124 Lublin, Szkolna 18, Poland

^dInstitute of Rural Health, Lublin, Poland

^eDomestic and Specialized Medicine Centre “Dilmed” Katowice, Poland

Abstract One of the most important dermatologic diseases from the sociologic viewpoint has been leprosy. Those with leprosy were isolated, excluded from society, and stigmatized. Such a stigma indicates the strong feeling that a leprosy patient is shameful and should not be accepted by society. During the first millennium, leprosy was rapidly inscribed in the system of religious prohibitions—the disease was a punishment by God for wrongdoing, and the disease was associated with the lower spheres of the society. Social perception of leprosy gradually changed during the time of Crusades. The care for lepers became a Christian obligation, and celebrating Holy Masses as for the dead was forsaken. The sick were forced to stay at leprosaria, particularly from the 14th through the 19th centuries when fear of leprosy was at a high point. Admission to a leprosarium was mandatory not only for patients with leprosy but also even those suspected of having the disease.

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Introduction

For centuries, one of the most important dermatologic diseases from the sociologic viewpoint has been leprosy. Affected people were isolated, excluded from society, and stigmatized. The stigma due to leprosy represents a social stigma, associated with a strong feeling that a leprosy patient is shameful and not to be accepted normally by society. It is also called a leprosy-related stigma, leprostigma, and the stigma of leprosy.

The stigma due to leprosy has been universal. It affects the physical, psychological, social, and economic well-being of patients.^{1,2} The age-old social stigma associated with the advanced form of leprosy lingers in many areas and remains a major obstacle to self-reporting and early treatment.³ Society maintains negative feelings toward people with leprosy. Problems of divorce, unemployment, and displacement from area of residence are common in people affected with leprosy.^{4,5}

Psychiatric disorders are highly prevalent in people with leprosy and these preoccupy the health care resources.⁶ Patients with leprosy were more likely to have psychiatric disorders than those suffering from other skin conditions.⁷ Leprosy is the most common cause of peripheral neuropathy

* Corresponding author. Tel.: +48 505 074 224.

E-mail address: ae.grzybowski@gmail.com (A. Grzybowski).

in the world; its complications can cause gross deformities of the face and extremities of infected individuals as well as crippling disabilities involving sight and touch. Such stigmata intensified the social and economic isolation of patients. The social consequences of the disease on the life of the patient persist even after its cure.⁸ Some employers refused to employ even a cured leprosy patient.⁶

The stigma of leprosy is still a global phenomenon, occurring in both endemic and nonendemic countries. Despite enormous cultural diversity, the areas of life affected are remarkably similar. They include mobility, interpersonal relationship, marriage, employment, leisure activities, and attendance at social and religious functions.⁹

Changes in the social perception of the disease

Leprosy was connected with the clearly visible and stigmatizing manifestations of the disease, including facies leprosa and changes in the area of palms, as well as the legs. It was also visible in the sanctioned system of warning, including bells, rattles, knockers, and bright robes marked with the yellow cross or a letter *L*, from the Latin word *leprosus*. Finally, to avoid being touched, they were armed with the sticks, as well as being given different and separate communication tracks, including separate entrances and windows for receiving meals. Deprived of many rights (eg, not being allowed to marry) and rejected by their families, lepers were forced to stay in leprosaria, peculiar ghettos known as leper colonies, which, however, had a strong and profound epidemiologic justification, taking into account extreme infectiousness of the leprosy.

The stigmatization and segregation of the leper was also reflected by the custom and duty of burying them at the separate cemeteries.^{10,11} The first leprosaria emerged with the increase of incidence of leprosy in the fourth century, and within the next 200 years they had spread throughout Europe. The disease usually touched the lower spheres of the society, where factors such as malnutrition, crowding, and lack of hygiene contributed to its development.

Social attitudes and approaches toward leprosy and the leper have evolved over many hundreds of years. In Europe, during the Middle Ages, leprosy was fast inscribed in the system of religious connotations—the disease was a punishment by God for wrongdoing.^{11,12} The sick were isolated, rejected in the social dimension, excluded from their community, and deprived of a majority of rights (they were not allowed to marry and had to leave their families).¹³

From the 11th century CE, during the time of Crusades, social perceptions of leprosy gradually changed, with the disease affecting many famous knights and rulers.^{11,12} King Baldwin IV of Jerusalem was called the Leper or the Leprous and had to wear a silver mask due to the skin manifestations of leprosy.^{14,15} During this era, leprous Crusaders were invested with a kind of holy aura, and sufferers from leprosy

came to be called Christ's poor. Care for the leper became a Christian obligation, and Holy Masses were celebrated in the honor of the lepers, as if they were dead. The Military and Hospitaller Order of Saint Lazarus of Jerusalem was established to help the diseased.^{10,12}

The sick were forced to stay at leprosaria (in 13th-century France alone there were approximately 2000 such places). Leprosaria provided treatment and safe living quarters, eased tension among the healthy townspeople, and provided for a more stable populace for the authorities to govern.¹⁶

The change in perceiving the problem of leprosy over the centuries can be pictured also by the leper colonies. The first leprosy houses emerged with the increased incidence of leprosy in the fourth century, and within the next 200 years they appeared throughout Europe. The leper colonies, for many centuries, constituted the form of seclusion and segregation of the sick and functioned as sorts of prisons, monasteries, and almshouses¹²; however, over time, when the contagious character of the disease and the necessity of isolating the sick became understood, the leper colonies were changed into hospitals and were crucial for the protection of public health.¹²

In the social consciousness of Western civilizations, leprosy is no longer associated with European countries, although before the mid-20th century, cases were reported in Albania, Romania, Greece, Italy, Spain, and Norway.¹⁷ The last of the European leprosaria (founded in 1900) is still open, located in eastern Romania in the Tichilești village in Tulcea County, and in 2011 was treating only 19 patients.¹⁸

Current views

In the social consciousness of Western civilizations, leprosy is no longer associated with European countries. Contemporary leprosy is treatable, but there are cases of stigmatization and discrimination also in developed countries. Even today, people affected by this disease have to leave their villages and are socially isolated. Depression is the most common psychiatric disorder found in these patients.¹⁹ For example, Japan had a unique history of segregation of patients into sanatoria based on leprosy prevention laws of 1907, 1931, and 1953, and, hence, it intensified leprosy stigma. Men admitted to leprosaria in Japan were sterilized, and women found to be pregnant were forced to have abortions. These extreme actions were done to prevent children of diseased parents from being born lest they also contract the disease. Doctors during this time still mistakenly believed that leprosy was a hereditary disease. The 1953 law was abrogated in 1996. There were still 2717 ex-patients in 13 national sanatoria and 2 private hospitals as of 2008.²⁰

To reduce social implications of the disease, there was a debate in the 1960s and 1970s about the choice of an appropriate name for this disease—leprosy, lepra, leprosy, or

Hanseniasis.²¹ A strong movement developed in some countries to substitute the name *leprosy* for leprosy.^{22,23}

Conclusions

Leprosy is among the world's oldest and most dreaded diseases. It plays a unique role in the history of mankind due to the numerous centuries of rejection and segregation of individuals suffering from leprosy as well as whole societies afflicted with this disease. The rejection and segregation were often the result of common fear due to lack of knowledge and there being no effective diagnosis or treatment of the sick. It was also connected with the clearly visible and stigmatizing manifestations of the disease. Even today, people affected by this disease may have to leave their villages and are socially isolated.

Disability in leprosy is more than a mere physical dysfunction; it includes activity limitations, stigma, discrimination, and social participation restrictions. The general public should be made aware that leprosy is not a genetic disorder, it is 100% curable, and patients need social support.

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