A Disease and Its Specter

Leprosy, Racism, and Public Health. Social Policy in Chronic Disease Control. ZACHARY GUSSOW. Westview, Boulder, CO, 1989. xiv, 265 pp. $25.

Leprosy has always been considered the epitome of a stigmatized disease, both feared for its physically deforming qualities and thought to be highly contagious. It has often been assumed that the modern prejudice against those affected can be traced directly back through history to earlier outbreaks as well as ecclesiastical writings. In *Leprosy, Racism, and Public Health*, Gussow challenges this assumption in a carefully argued, rigorously researched, and methodologically sophisticated account of the disease as manifested in modern Western culture.

Gussow contends that the stigma associated with leprosy is neither universal nor historically continuous. Rather, he suggests that the stigma is a "culture-bound syndrome," the result of a specific set of cultural, political, and historical forces. Such a thesis requires a thorough introduction to the major social forces and thought of an era; Gussow therefore goes to significant lengths to delineate the social and political environment in which leprosy came again to be feared and loathed.

In the late 19th century, as Western nations laid claim to colonial empires, deep concerns about leprosy were revived. Contact with "inferior peoples" offered the possibility of contagion; leprosy both symbolized and substantiated these fears. Fear of leprosy became, for example, a central theme in efforts to limit immigration to the United States in the late 19th and early 20th century. Although prevalence of the disease in the United States never amounted to more than several hundred cases according to the most meticulous surveys, the specter of a widespread epidemic was frequently cited in Congress to justify restrictions on immigration, especially from China. Immigrants from the Far East were singled out as representing a particularly ominous threat to American culture and health. Branded the "yellow peril," the Chinese were blamed for cases of leprosy in Hawaii as well as on the mainland. Gussow effectively demonstrates how such views reflected a social Darwinian logic characteristic of the era. A virulent racism shaped the meaning of leprosy and, in turn, social and medical responses to those afflicted.

In Hawaii, for example, as concern about leprosy heightened, those afflicted were exiled to the island of Molokai, where a colony was established in 1866. This policy of isolation was implemented by Westerners in Hawaii fearful of the importation of leprosy among Chinese laborers and native-born populations. In Hawaii, racial prejudice constituted the principal force behind isolation, which was opposed by the natives. In 1873, Father Joseph Damien took over the direction of the colony, working to improve the deplorable conditions there. But Damien's contraction of leprosy, followed by his death in 1889, became a powerful symbol of the dangers of the disease and was repeatedly cited to justify the isolation of leprosy patients. In the United States, such facts were quickly incorporated by a growing anti-immigration movement.

In this context, according to Gussow, leprosy became a moral issue. Grossly exaggerated accounts of the contagiousness of leprosy and the deformity it produced eventually led the U.S. Congress in 1917 to establish a national leprosarium at Carville, Louisiana, where patients throughout the United States would be sent. There a "colony" was created, a unique institution (still in existence) where patients would often spend their entire lives. Gussow aptly describes the complex sociocultural qualities of this institution and its inhabitants. The institution served several goals: it isolated those with leprosy from the general population, and it provided a "refuge" where those with leprosy might be spared the stigma and prejudice associated with the disease. As Gussow points out, however, the very isolation often had the effect of encouraging the stigmatization that patients hoped to avoid. Moreover, the internal ideals of the institution often reinforced the stigmatization. The U.S. Public Health Service, for example, paid employees "hazard duty pay" even though risks of working with the leprosy patients were minimal.

In addition to the social and political forces of racial prejudice, Gussow suggests that religious missions of the 19th and 20th centuries contributed to the "restigmatization" of leprosy. Christian missionaries sensationalized leprosy and its victims with horrifying descriptions of deformity and debility, making explicit links with ecclesiastical texts. By equating modern victims with biblical "lepers" and emphasizing a view of the leper as "ultimate sufferer" these groups heightened the fear and stigma of the disease.

To demonstrate the particular and historically specific nature of these assessments of leprosy, Gussow contrasts U.S. policies with those of Norway. During the late 19th century, Norway became a leader in the medical treatment of and scientific research on leprosy. Upon the discovery that leprosy was hyperendemic among its rural poor, clinics and treatment centers were established to provide medical care. In 1873, Armaurer Hansen, a Norwegian physician and researcher, employing the new techniques of bacteriologic research, discovered *Mycobacterium leprae*, the infectious agent that causes leprosy. While Hansen's discovery intensified existing concern about the contagiousness of the disease, the actual mode and ease of infection remained obscure; further research demonstrated that only prolonged and intimate contact led to infection. Although Hansen argued for isolation, the Norwegian response continued to emphasize medical approaches and further research. In the United States, however, racial fears overwhelmed all rational assessments; public health focused on segregation of patients rather than treatment or research.

In a brief coda, Gussow describes the "secularization" of leprosy since World War II, a process that has been furthered by the introduction of sulfa chemotherapies, the decline of colonial empires, and the work of the World Health Organization. WHO, in particular, has worked diligently to end the isolation of individuals with leprosy. Nevertheless, even as the heavy stigma of racial and religious views has dissipated, leprosy remains a serious problem with more than 10 million cases worldwide, most of which remain untreated.

Gussow has provided a sophisticated interdisciplinary approach to understanding the nature and meaning of chronic disease. By combining anthropologic insight with historical analysis he demonstrates how disease may come to be used as a symbol, how it can take on powerful social functions. These meanings, however, often may conflict with the goal of providing humane, scientifically based medical care to those affected. By examining the particular historical and cultural values that may lead to the stigmatization and isolation of victims of disease, Gussow offers a critically important lesson for our own time.

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