

SOCIO-CULTURAL ATTITUDES TOWARDS
HANSEN'S DISEASE (LEPROSY)

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The word "leprosy" has for millennia evoked feelings of horror, of mutilation and disfigurement, and of social ostracism. Attitudes towards the afflicted persons have often ranged from social exile to profound compassion for beings so unfortunate. From ancient times, as with most disease, supernatural causation and comparable methods of treatment have been the rule. In addition, in many societies, leprosy is considered to be punishment for moral faults. And in all societies, the overriding question is: what to do with the leper?

This paper is an expression of an interest in leprosy and its treatment and the socio-cultural attitudes from non-lepers to patients, as well as those of the patients toward themselves. This writer worked as an educational missionary in the Virgwi Leprosarium in northeastern Nigeria for about eighteen months, a quarantined reserve of 5,000 acres, serving about 1,600 patients from almost fifty tribal societies. Although his work was primarily in the school, which had about 450 children whose disease had brought them to the leprosarium, he usually sat in on admission and treatment clinics and other medical activities, in addition to a variety of non-medical, non-education ones, from maintaining machinery and vehicles to making peanut oil soap.

Historically, almost certainly, diseases whose superficial symptoms resembled leprosy were considered to be leprosy, and the victims subjected to the prevailing treatment and attitudes towards the disease prevalent at whatever time, and also quite

likely so-called cures, seemingly miraculous, were of diseases other than leprosy. The association of leprosy with the bacillus Mycobacterium leprae was proposed by Dr. G. H. Amauer Hansen in 1864, though the proof usually demanded by medical research since the time of Koch, namely that the organism be isolated in a living being, then grown outside the host and inoculation and infection of a healthy host, was not possible until 1965 with the development of successful laboratory techniques. However, Hansen's theory was almost universally accepted because of the presence of the organism in diseased persons, its absence in healthy ones and its specialized effect on body cells (Brady 1974:22).

Leprosy is unquestionably contagious and in some areas of the world, especially Africa and Asia, is endemic, with an estimated total of ten million cases worldwide. There seems to be considerable difference of opinion as to the level of contagion and indeed the disease exhibits decidedly different degrees of severity in different areas. However, the disease seems to resemble other Mycobacterium infections, such as tuberculosis (Mycobacterium tuberculosis) in that rather extended intensive contact with an infected person seems to be necessary. No accurate measure of this has been established, but authentic cases reveal a latent period from six months to twenty years, with an average of three and one-half years required for incubation (Brady 1974:23-24). The close association of leprosy with tuberculosis is seen in medical conferences and symposia which frequently considered both diseases simultaneously. (Wolstenholme and Cameron 1955:340ff). In northeastern Nigeria

where this writer worked, however, tuberculosis was very rare, though leprosy most certainly was not.

Howard Bosler, M. D., superintendent of the Virgwi Leprosarium, colleague of this writer and a recognized authority on leprosy in West Africa, expressed an opinion also held by other authorities, that children seem much more susceptible than adults, and given the lengthy incubation period, varying from months to several years, Dr. Bosler felt that many, if not most patients were infected as children, with the symptoms not becoming manifest until adulthood. He also stated that in his opinion it would be very difficult for a healthy adult to contract the disease (Personal Communication). It also seems quite uncommon for more than one member of a family to have the disease, with spouses and children seemingly non-infectious to each other, in spite of close social contacts, including sexual relations. In the Virgwi Leprosarium, patients were permitted annual furloughs of one month, returning to their homes. In fact, the quarantine maintained was much more rigid in preventing unwarranted movement in and across the area, rather than restricting the patients.

In common with all organisms, the bacterium responsible for leprosy is subject to natural selection and variant strains of the disease have been identified in present-day populations and quite likely the diseases identified by the ancients, if indeed were truly leprosy, might well have differed from modern forms in some details. However, there are certain symptoms found in all variants and even the ancient records told of anesthesia and numbness, as well as skin manifestations ("as white as snow"),

muscular lesions, and lepromatous nodules, all of which are found today.

Both anesthesia and macules may appear in the early stages of the disease, along with minor paralysis of hand and facial muscles. As the disease advances, the body tissues may set up effective defenses, containing the disease against further development, though crippling deformities may eventually develop. This form of the disease is called "tuberculoid" and is considered relatively benign. If, on the other hand, body defenses are inadequate, a progressively severe form called "lepromatous" ensues. Intermediate types between these are frequently found also, with some areas of the body showing more involvement than others. The reaction of the body to the presence of the bacillus may be relatively slight in the tuberculoid form, though some lesions may occur along with ulceration and edema (fluid accumulation), especially in the legs and under the eyelids. The symptoms of the more severe forms of the disease are similar to these, but are much more intense and more of the tissues and organs are involved. The nervous system may become infected with severe paralysis and crippled deformations resulting (Brady 1974:29-30).

Deformity accompanying advanced cases of leprosy may include the anesthesia and muscle paralysis, including the inability to close the eye. The skin may become puffy and sag, especially on the face. When tendons are involved, crippling of the joints, especially in the hands and feet, may result, and the digits may become shortened, and often cartilage is affected, with stiffening of the joints. Atrophy

of the testes may cause changes in the secondary sexual characteristics. Due to the lack of sensation, infections easily result from injuries and burns, and amputation may become necessary. The muscle paralysis may prevent normal positioning of hands and feet, and clawing of hands and toes results. Severe necrosis in facial tissues, and cartilage and mucous membranes, along with edema of the soft tissue may give a "leonine" or "lion-like" appearance, while the lesions in the throat may severely affect speech. In spite of this list, quite abbreviated, of the external features of the disease, almost all those found in leprosy are duplicated in other diseases, and beyond doubt have complicated enormously the proper diagnosis, with unknown numbers of victims over the centuries being designated as lepers, with all the social attitudes directed at lepers being diverted to them. (Brady 1974: 31-32).

There is serious doubt that the disease called "leprosy" by ancient Semites, including the Hebrews, was truly leprosy, and the words translated as "leprosy" denote defilement, a religious or ritual concept, not clinical in the modern sense (Cochran 1964:2). In fact throughout history, both in Europe and Asia, one may question the proper usage of the term, either in diagnosis or treatment, and in socio-cultural attitudes towards it. However, any resemblance the modern form may or may not bear to these earlier afflictions, certain elements are the same: the disease usually carries the burden of cultural beliefs that it is supernaturally caused (along with all disease), that it is contagious, though in what way may well be misunderstood, so that some form of isolation is necessary,

and it is so massively horrible an affliction that one who was leprous was most unfortunate, and thus logically, one who aided a leper was performing an act of extraordinary virtue and merit.

Through the centuries diagnosis of leprosy was as much a part of ecclesiastical authority, i.e., of the supernatural as it was the medical (hardly more scientific before modern times). From the edicts of Leviticus, throughout the centuries of Judaism and later Christianity, the priest and the physician were both involved, and the stigma of moral fault usually accompanied the diagnosis of the affliction, and certainly few misfortunes could be so much feared as to be condemned to a future of disfigurement and separation from family and society, all the more terrible because even the inevitable death would come only after years of suffering. The leper might be bathed and fed in one town, burned alive in another; vilified by some, an object of deepest sympathy to others while his legal status was most precarious, almost as though he were already dead (Brady 1974:82-83).

In Africa, an area in which leprosy has long been endemic, it is noteworthy that no connotations of moral fault are ever attached to leprosy as such, though presumably the disease might be sent by the ancestors, spirits or gods for the transgression of a tabu, intentional or unintentional. Morality, on the other hand, is primarily a matter between persons, not men and the supernatural beings. Understandably, leprosy is viewed essentially as a terrible misfortune, and the leper a most unfortunate being, but most certainly not a societal outcast.

However, rather than simplifying the problem, it poses more of a dilemma, because in common with most peoples, the Africans fear the contagion of the disease. One simply does not exile a brother, sister, parent or child or anyone in the village because he has leprosy. This writer posed a situation asking whether one should eat out of the dish of food offered to one by a leper. Unanimously, the answer was that one would have no alternative, to refuse a proffered gift of food from a leper would be most reprehensible - in effect saying that one had ceased to be his brother. All agreed, including students with training in Western science and medicine, that in spite of the chance of contracting the disease, they would unquestionably share the leper's offer of food.

How then does the African deal with this disease? In contrast to the concept of ritual defilement of the ancient Hebrews, or the moral turpitude associated with the disease by medieval Europeans, the African seems to view this malady as one of many afflictions which are a part of life, differing primarily in that it is much worse in its long, tortuous duration and its crippling deformation than many of his diseases. Of course, he will attempt to ward off the disease by appropriate charms, talismans or other devices and measures which hopefully provide the supernatural power essential in overcoming the supernatural powers responsible for the disease, and if he still contracts it, his faith in the measures tried remains intact. They failed because they were not strong enough to overcome the conflicting power, perhaps inflicted upon him by a witch or sorcerer or perhaps a capricious spirit-being.

In a similar fashion the attitude of the society to the leper reflects most of the basic social organization patterns of kinsmen and fellow-villagers. The privileges and obligations which are a part of these relationships are not abrogated by the presence of this disease. Even though there is recognition of the possibility of contagion, there is not the utter rejection of the leper from normal society, no more than for other diseases, and since for many lepers, the symptoms are neither acute nor debilitating, at least in its early stages, lepers may lead relatively normal lives for years. The disease itself is rarely fatal, and most lepers die from secondary infections brought on by a general weakened condition, or may survive twenty or thirty years in a gradually deteriorating condition, becoming more and more dependent upon the care of others.

In Africa as elsewhere in the non-western world, the family or extended kin group has the responsibility for the individual, both in controlling and assisting him. This responsibility is maintained by the family whose member may be leprous. Far from being rejected, he remains what he has always been, imbedded in a social milieu, surrounded by his kinsmen, secure in the knowledge that their solicitude will not diminish. It is his right and privilege, it is their obligation. Whatever resources the family has for his care and treatment are available for him. His only responsibilities lie in avoiding, if possible, unnecessary situations of contagion. By extension, his fellow villagers will continue to maintain relatively normal relationships, perhaps coming to salute him even more in his sickness than when he was healthy.

Contrast this with the patterns of rejection of a leper, found in much of the world, including modern industrial societies. Even with the knowledge that a leper who is undergoing treatment with modern drugs including sulfones and antibiotics, many of which are quite effective, will be completely non-infectious within a few days after inaugurating the course of treatment, most of us recoil with some visible signs of repugnance at the thought of contact.

In spite of much knowledge, we still harbor unreasoning prejudices and fears of some diseases, imputing moral turpitude to those unfortunate enough to be afflicted. How do we treat the mentally disturbed, the alcoholic, the sexual deviant? Add to this list the leper, whose disease is to us a linguistic symbol of rejection. On the other hand, the "ignorant" African, ridden by fears of the spirit world, will extend his hand to a leper who comes to his gate, and say, "Maraba" (welcome").

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