

## CLINICAL NOTES

*Editor's Note: In an effort to increase the utility of the JOURNAL in continuing medical education, it has been suggested that a new feature of the JOURNAL be added on a trial basis to the Editorial Section—Clinical Notes. In this section, we welcome contributions dealing with practical problems in leprosy work. Submissions to this section will undergo minimal editorial changes and may well contain controversial points. Letters to the Editor pointing out other viewpoints are welcome.—RCH*

### Influence of Social Perceptions of Leprosy and Leprosy Patients on Public Health Programs

Leprosy is regarded as a dreadful disease in many parts of the world.<sup>1-3</sup> Not only is it considered as a serious and disabling illness, but also as a stigma often associated with fear and shame.<sup>4</sup> The importance of understanding the social perceptions of leprosy has been emphasized for community education,<sup>1, 2, 5</sup> but the influence of these perceptions at a national level on epidemiological studies and preventive programs has been little analyzed as such.<sup>6</sup> In Senegal, where the prevalence rate is 2.7 per thousand, i.e., 15,500 cases (a figure which is thought to be underestimated by one half), with 21.8% multibacillary forms,<sup>7</sup> leprosy is an important problem of public health,

but it has been little studied from an anthropological point of view.<sup>8</sup>

Within the context of a research program on "urbanization and health" in the underprivileged suburbs of Dakar, we undertook a study on social perceptions of leprosy. Field work was done from 1984 to 1986, and consisted mainly of interviews with the two doctors in charge of the national prevention program, with 12 traditional healers belonging to seven different ethnic groups, and with 25 leprosy sufferers met in the surroundings of the cathedral of Dakar.<sup>9</sup> The results presented here are mainly taken from the in-depth interviews with the traditional healers (all of them were seen between three and ten times during the 2 years of research). This methodology differs from the one usually chosen, using questionnaires in large populations,<sup>1-3</sup> because we think that for diseases involving such social perceptions the responses to surveys do not reflect the complexity of representations and practices. The 12 healers were not specialists in leprosy. They all had been born and brought up in the village and had come later into town; two were Wolofs, two Fulas, two Tukulors, two Soninkes, two Diolas, one Serer, and one Bambara.

**Representations of leprosy.** In most languages of Senegal, leprosy is called "the great

<sup>1</sup> Kaufman, A. E. *La lepra y sus imágenes. Enfermedad estigmática y muerte social*. Madrid: Centro de Publicaciones, Ministerio de Trabajo y Seguridad Social, 1985.

<sup>2</sup> Cook, A. An urban community's thoughts about leprosy: a survey in Guyana. *Lepr. Rev.* 53 (1982) 285-296.

<sup>3</sup> Vyas, G. K., Dudani, I. U. and Chaudhary, R. C. A sociological study of leprosy cases in the Ghandi Kusth Ashram, Jodhpur (Rajasthan). *Lepr. India* 54 (1982) 324-331.

<sup>4</sup> Goffman, E. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, N.J.: Prentice-Hall, Inc., 1963.

<sup>5</sup> Kaufman, A. E., Neville, J. and Senkenesh Gebre, M. *La Dimension Sociale de la Lèpre. Manuel d'Enseignement pour les Agents de Santé*. Paris: ILEP, 1983.

<sup>6</sup> Pearson, M. Social factors and leprosy in Lamjung, west central Nepal; implication for disease control. *Ecol. Dis.* 1 (1982) 229-236.

<sup>7</sup> Ministère de la Santé Publique. *Rapport Annuel sur l'Académie Lépreuse au Sénégal, 1982*. Dakar: Services des Grandes Epidémies.

<sup>8</sup> René, J. P. *Approche psychologique de la lèpre et prévention de ses complications en milieu rural*. Thèse de Doctorat en Médecine, Dakar, 1987.

<sup>9</sup> Fassin, D. *Thérapeutes et malades dans la ville africaine. Rapports sociaux urbanisation et santé à Pikine, banlieue de Dakar*. Thèse de Doctorat à l'Ecole des Hautes Etudes en Sciences Sociales, Paris, 1988.

disease" (for instance, *feebur bu mag* in Wolof), circumlocution which wards off the evil by avoiding to name it (*ngaana* in Wolof), as it has been also noticed for another dreaded disease, measles, which is referred to as "the good mother."<sup>10</sup> Leprosy is feared for its gravity, its incurability and its stigmatizing manifestations, but also for the questions it poses and the interpretations it requires. Although it is known to be contagious, it appears to affect only certain persons in a community or in a family, thus raising the question, why them?, i.e., the problem of meaning.<sup>11</sup>

For all ethnic groups of sahelian Senegal (excluding the southern part, i.e., Casamance), leprosy is interpreted as the transgression of an interdict. This taboo can be of three types—sexual, social, or food-related—which are not exclusive for a given healer (a case can be interpreted in one way and the next one in another). The breaking of a sexual interdict consists of having intercourse with a woman during her menstruations. The child thought to be born of this union will have leprosy when he grows up; depending on the characteristics of menstrual blood, the disease will be "red leprosy," "black leprosy," or "white leprosy" (at the end of the period when sperm becomes more abundant than blood). The breaking of a social interdict is invoked when a marriage happens between two castes or clans whose alliance is prohibited. For example, among Fulas and Tukulors, the marriage of a blacksmith (*baylo*) or a weaver (*maabo*), or among Soninkes and Bambaras, the union of a Drame family and a Diakhate family. Finally, the breaking of a food interdict concerns either silurid in the Senegal River Valley where fish is part of the everyday meal, or brown-spotted goats in the desert areas where people are mostly nomads tending their flocks.

The causal interpretation of leprosy, usually done by a seer, depends on the social context and is always given *a posteriori*,<sup>12</sup>

which enables society to present the "right" explanation. If a prohibited alliance is found in the lineage, the designation of the cause will serve as a warning for subsequent transgressions, but most of the time there is no such breaking of a social interdict. One chooses simply between two solutions, one of which (sexual) is more degrading than the other (food), on the basis of the social positions of those suffering from leprosy and the will to harm them. In any case, the interpretation as a transgression reinforces and legitimizes the physical stigma, giving leprosy its image of impurity and stain.<sup>13</sup>

The only etiological model which differs completely is the one found in the forests of Casamance, south of Senegal, among the Diolas. Knowledge and power of leprosy is thought to belong to the clan of the Diediou, masters of the forge: *kafaan̄ak* means, simultaneously, the ritual possessed by the clan, the altar on which it is done, the disease which it can provoke, and the forge where the men work. One becomes a "leper" by two different means. For a Diediou, leprosy is caused by a mother or grandmother who has forgotten to accomplish the clanic ritual. For a person of another clan, it is attributed to a harmful action directed toward the Diediou, who take revenge by giving the disease. The secrets of healing belong to the same clan and the treatment necessitates long ritual procedures, and so the Diediou often have several leprosy cases living in huts around the main house and receiving herbs for the work they do in the fields or in the village. Among the Diolas, leprosy is only one of the numerous diseases or misfortunes caused by the forgetting of a ritual.<sup>14</sup>

Messages in health education must take into account both the empirical knowledge about transmission and the theoretical framework for interpretation. Educational programs must be realized at the local level rather than at a national one in order to be adapted to different cultures and societies.

<sup>10</sup> Fassin, D. "La bonne mère." Pratiques rurales et urbaines de la rougeole chez les femmes haalpulaaren du Sénégal. Soc. Sci. Med. 23 (1986) 1121–1129.

<sup>11</sup> Evans-Pritchard, E. E. *Witchcraft, Oracles and Magic Among the Azande*. Oxford: Clarendon Press, 1937.

<sup>12</sup> Sindzingre, N. and Zempleni, A. Modèles et pragmatique, activation et répétition: réflexions sur la cau-

salité de la maladie chez les Sénoufo de Côte d'Ivoire. Soc. Sci. Med. 15B (1981) 279–293.

<sup>13</sup> Douglas, M. *Purity and Danger*. London: Routledge and Kegan Paul, Ltd., 1967.

<sup>14</sup> Fassin, D. and Badji, I. Ritual buffoonery: a social preventive measure against childhood mortality in Senegal. Lancet 1 (1986) 142–143.

It can be expected that acceptance and observance of treatment will be improved if therapeutic choices are not disconnected from traditional beliefs and practices.

**Images of the leprosy patient.** If leprosy is dreadful, it is also because some leprosy sufferers are dreaded. In most languages expressions can be found stigmatizing them. In Wolof, one says "mean as a leper." Two similar stories (one told by a healer, the other by a nurse), both mentioning they had witnessed the event as children, illustrate this feature. Two leprosy patients had spoiled the meals of the villagers by putting their hands respectively in a jar full of water and in the food displayed at a market place. They had brought upon themselves the anger of the villagers and had eventually been beaten or stoned to death. Veracious or invented, these stories—heard from two distinct informers—indicate the prejudice of many people, associating impurity and malice with leprosy and justifying the exclusion and bad treatment of those with leprosy. In some way, this stereotype even seems to be the model on which leprosy sufferers adapt their own behavior. Since everybody says they are evil, they have to behave as such and become what society wants them to be—aggressive and provocative.<sup>15</sup>

Nevertheless, all ethnic or geographic groups do not develop the same attitudes toward leprosy patients. If one simplifies one can distinguish three types of behavior. In the center (mainly, Wolofs and Seres), the leprosy patient is usually associated with danger. He is rejected out of the house, on the outskirts of the village, i.e., where wilderness begins. He does not participate in collective activities, such as meals, and uses his own latrines. In the Senegal River Valley (where Tukulors, Fulas, Soninkes and Bambaras live), the leprosy patient is integrated into the group. He lives within the same house where he usually has a separate room; he shares meals with other villagers but utilizes a spoon instead of his hands; he does not have a specific place for performing his ablutions. Finally, in Casamance (where Diolas, Mandingos, Manjaks are preeminent, except in the eastern part where Fulas

are more numerous), the already mentioned interpretation of leprosy gives an original configuration. Leprosy patients are grouped together in the house of the Diediou family where they receive ritual treatments in exchange for their work in the fields. Famous healers thus have large houses with many patients who share their meals and live in the same spaces.

This analysis not only provides anthropological data, it also gives a better understanding of the problem encountered by public health programs in Senegal during the 1970s. Against leprosy, the same strategies of prevention (therapeutic villages for leprosy patients) have been used throughout the country without consideration of cultural and social peculiarities, leading to very differentiated responses from the different populations. In the center, the therapeutic villages have been relatively successful since they permitted the people to get rid of leprosy patients. Four centers were opened for an estimated 7400 cases in 1982. In the Senegal River Valley, on the contrary, the program turned out to be a failure since the two therapeutic villages hardly received any patients, most families preferring to keep their ill kin in the house (3940 cases had been counted this same year). Finally, in Casamance the model of therapeutic villages has been well accepted since it appeared as a modern continuation of a traditional practice. In the early 1980s six such centers received patients and their families (for only 2560 cases identified). A study of social perceptions of leprosy and those with the disease might have helped to anticipate these results.

Such a study is necessary to interpret and critique epidemiological data.<sup>6</sup> In 1982, the lowest prevalence rates among the nine regions were seen in Louga (1%)—the only one with no specific program—and Dakar (1.4%). By comparison, these rates were 2.4% to 3.2% in the center, 2.5% to 7.4% in the Senegal River Valley, and 2.6% to 4.8% in Casamance.<sup>7</sup> One could have thus inferred that leprosy was less frequent in urban than in rural areas. But when a close look is given to practices toward those with leprosy in Dakar, two facts are noticeable. First, social tolerance seems lower than in rural areas, and urban families often send their ill parent back to the village. Secondly,

<sup>15</sup> Kumar, J. H. R. and Verghese, A. Psychiatric disturbances among leprosy patients; an epidemiological study. *Int. J. Lepr.* 48 (1980) 431–434.

political choices were made in the 1960s to clear "human clutter" out of the city, and one of the means proposed was the creation, by the law 65-27 of 4 March 1965, of therapeutic villages where leprosy patients were forced to go<sup>16</sup> when a risk of contamination was estimated. Thus, progressive exclusion by families and brutal deportation by the police have produced a significant and artificial decrease in the urban prevalence of leprosy.

Social perceptions of disease are often neglected in public health programs in developing countries. However, their study may bring indispensable knowledge, not only in educational activities, but also in the choice of preventive strategies and in the interpretation of epidemiological information.

This investigation, carried out among traditional healers and leprosy sufferers belonging to different ethnic groups and living in urban conditions, had the precise objective of focusing on representations and practices concerning leprosy and leprosy patients.

Contrary to what is often believed, there is not a single interpretative model of this disease, neither is there one specifically for each ethnic group. In Senegal, two general explanations are given—one in terms of taboo, the other in terms of clan. The first one, predominant in sahelian areas, varies greatly according to not only the cultural but also the environmental and social context: the type of interdict can thus be related

to sexuality, marriage, or food (the latter depending on the fish or meat locally available) and the interpretation is adapted to the personal status and family history. The second one, found in the southern forests, makes one of the clan groups responsible for giving and curing the disease.

Although equally feared among the groups studied, as it appears in the paraphrases used to avoid naming it, leprosy induces extremely different behaviors. Populations from central Senegal reject their patients, which explains, at least partially, the relative success of the therapeutic villages policy in this area. Conversely, inhabitants of the River Valley integrate their cases in their everyday life, refusing to send them to the segregated centers of the national program. Finally, in Casamance, where there exists a tradition of grouping together leprosy sufferers in order to treat them, the modern structures are functioning well.

Preventive as well as curative activities must thus rely on anthropological data permitting their adaptation to specific social and cultural contexts.

—Didier Fassin, M.D., Ph.D.

*Institut Santé et Développement*  
15 Rue de l'École de Médecine  
75270 Paris Cedex 06, France

Dr. Fassin's present address is: IFEA Mission ORSTOM, A.P. 6596 CCI, Quito, Ecuador.

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<sup>16</sup> Collignon, R. La lutte des pouvoirs publics contre les "encombres humains" à Dakar. *Can. J. Afr. Stud.* 18 (1984) 573–582.