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Leprosy—as seen by the patients

Observations made in the Philippines suggest that intensive studies on the social aspects of leprosy would result in improved control programmes in areas where the disease is endemic.

The continued presence of leprosy in 33 developing countries of the Western Pacific region may be due to social factors that diminish the effectiveness of treatment, including:

— personal views on disease etiologies;
— religion;
— ethnicity;
— family composition;
— level of poverty;
— environmental conditions, e.g., quality and quantity of water supply and sanitation;
— public health status of the community, e.g., nutritional status;
— political structure of the community;
— politics of leprosy control programmes and delivery systems.

With the growing recognition of the critical role of social factors in disease control, social scientists have begun to undertake research aimed at identifying obstacles to the control of leprosy. Some social scientists and medical practitioners are collaborating to develop an interdisciplinary perspective on health in general and leprosy in particular. Their efforts are encouraged by funding agencies, including the World Health Organization through its Special Programme for Research and Training in Tropical Diseases. This article reports on two interdisciplinary studies conducted in the Philippines on the social aspects of leprosy, with special reference to the socio-psychological dimensions of the disease (1, 2).

Perceptions and attitudes of leprosy victims

The treatment of leprosy is not solely the responsibility of medical practitioners. Patients’ adherence to treatment procedures is of the utmost importance. This, in turn, depends on perceptions and attitudes that are socially shaped. It is therefore necessary to look at patients’ typical responses and attitudes to the illness and at some factors that bring them about. One of the Philippines researches summarized the mode of development of the disease and patients’ typical responses to it in chronological sequence as follows (1).

• Onset of disease; problem of recognition when patients start to observe skin changes.
Leprosy

- Emerging disabilities; problem of uncertainty; patients start to feel and then complain about the effects of skin changes on their general well-being. They describe their condition as “feeling tired”, “weakening”, “weakening of the blood”, “lightness of body”, “dizziness”, “chill”, and “aging”. Since the changes are not very obvious, other people are usually unconcerned about such complaints at this point.

- Patients approach hospital specialists with mixed feelings and doubt their capacity to help. They are told they are suffering from the early symptoms of leprosy, given a card and a schedule for taking anti-leprosy medication, and feel relieved for a while, especially when the symptoms disappear.

- Patients start complaining of “physiological” discomfort like backache, itching, and a feeling of things crawling over the body.

- Patients may or may not return to their villages, but if they do, they consult a herbalist, whose diagnosis is that they are being “hexed”. The patients are given “leaves” to boil in their drinking-water and to put in their bath water.

- The patients still feel weak and go back to hospital.

- They are X-rayed. Their blood is declared clean, their lungs clear, and their hearts normal.

- This leads the patients to be convinced that the herbalist’s diagnosis is correct.

- The patients note that the skin changes are getting worse and that their general appearance is altering. They are left with two options: to stay in the village or go back to hospital. They opt for the first and seek other traditional healers or go to the same ones, who reinforce the earlier diagnosis and give more leaves to boil and more prayers to chant.

- The patients continue to suffer from fever, chills, and aches, and gradually come to accept that they have leprosy.

What happens when patients finally confront the problem and admit that they are sick? They may react in various ways and may experience negative feelings like fear, worry, shame, depression and anger.

Timing—without clocks

It was found that patients had difficulty in grasping schedules for visits of nursing attendants or for taking medicine. People who have not been taught about time and its division into hours, days, weeks and months find it difficult to keep to schedules. A similar difficulty arises in the patients’ reckoning of age and the duration of illness in years and months. The inability of patients to recall their age at the onset of the illness makes it difficult to collect the epidemiological data without which it may be impossible to improve leprosy control programmes.

The service providers had difficulty in giving instructions on the dosage of pills or capsules, and it was repeatedly necessary for them to give patients, or their relatives, slow explanations about the matter. The difficulty was compounded when there was a change in the medicine prescribed, e.g., when multidrug therapy was introduced. The service providers resorted to identifying the medicines by their colours so as to help the patients to remember which medicines had to be taken. Some doctors who were aware of the difficulty patients had with time adapted their instructions accordingly, e.g., by telling the patients to take their medicine not at a specific hour but when they got up in the morning. This factor is particularly
important in multidrug therapy, the success of which depends on the regular taking of medicine.

Socioeconomic status

Some 90% of the Philippines population is disease-prone owing to inadequate access to medical and health facilities (3). Furthermore, 70% of Filipinos are living far below the poverty line. One way to measure the relationship between leprosy and poverty is to examine the socioeconomic status of patients. Of 40 patients in one village, only nine were considered to be of high socioeconomic status. All the rest were poor. However, the disease may also be prevalent among rich people, for whom data are scarce in public hospital records.

Let us accept that poverty is a critical factor affecting the social dimensions of the illness. On this basis, if leprosy is to be defeated, it is necessary to find out how to restructure society so as to banish poverty and malnutrition.

Social stigma

People tend to stigmatize those suffering from the debilitating effects and disfigurements of leprosy. According to one report (4), most victims of the disease felt they were avoided and considered unclean by other members of the community. Some expected and accepted this but even so were adversely affected by it. On the whole, village officials claimed they did not mind associating with people suffering from leprosy, but beneath the surface this seemed not to be true.

At one study site, patients demonstrated self-stigma by using "we" instead of "I". For example, rather than saying "I went to see the doctor" they said "We went to see the doctor". They did this whenever they spoke of their illness or social reactions to it.

Stigmatization hindered case-finding and case-holding. Sufferers and their families hesitated or procrastinated in seeking treatment; some sought care away from their own locality for fear of being stigmatized. Some doctors tried to impress on their patients that allowing themselves to be affected by stigmatization would delay their recovery.

It has been suggested that the stigmatization of leprosy victims in the Philippines is a direct result of acculturation during the long colonial period and that segregation fostered myths about them and their illness and elicited fears among the rest of society, thus aggravating stigmatization. This implies that when patients are allowed to interact more with the healthy members of society, stigmatization may diminish. In contrast,

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studies in India explain stigmatization as arising from people’s fears when they see the disfigurements of victims.

Coping behaviour

Only a small proportion of patients reported to the skin clinic and took regular medication. Most of the rest went to faith healers, whose regimen typically included a potion to be drunk, ointment, and the
rubbing of saliva and/or betel nut on the skin. Patients said that this resulted in the symptoms disappearing, often to reappear later. They attributed recurrence to their own negligence, not to the ineffectiveness of the faith healers’ methods. Some patients sought advice from friends and relatives, who recommended them to drink a brew of carmay, guava, and banaba leaves, to rub garlic or certain proprietary ointments on the affected skin, or to apply a solution of salicylic acid.

More than half of the patients attempted to isolate themselves as much as possible in order to avoid negative experiences. Most maintained that praying for God’s help and mercy gave them solace and comfort in their isolation. Other forms of coping included cleaning the body and avoiding certain foods.

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The communities studied in the Philippines believed that leprosy was caused by irregular habits, exposure to wind, sudden changes in temperature, fatigue, faulty diet, emotional stress, supernatural influences, hereditary factors and/or psychic experiences. If these beliefs are not countered by health education they will make it difficult to reduce the confusion in patients’ minds regarding the transmission and treatment of the illness. Educational materials should therefore be prepared in local languages and distributed among leprosy victims, care providers and the rest of the community so as to increase their understanding of the disease.

Village health workers should be trained in case-finding and case-holding and, to a certain extent, in the giving of treatment. This should be part of a project involving the community in seeing to its own health care on a broad front.

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References

