THE SOCIAL ASPECTS OF LEPROSY[1]

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To appreciate the social aspects of leprosy and the need of the victims of the disease for social help, there are two basic things that must be borne in mind. One is the general attitude of the public toward these people. The other is the fact that there are two main classes of leprosy cases which usually are dealt with differently in public health measures.

Why is the public generally afraid of persons with leprosy? Only because the disease has been given the name *lepra*. Lepra is the Greek translation of the Hebrew word "zaräath," which according to Leviticus (Jewish Code of Law) means "Condemned by God." The ancient Jews in the days of Moses were said to be afflicted with *zaraath* for having disobeyed God or sinned against His commandments. The affliction was considered a blemish resulting from divine displeasure, and those who had it were to be shunned by the "clean" community. The Dutch word *melaats*, meaning "Struck by God," also has similar unpleasant religious associations.

It is for no other reason that people with leprosy are abhorred and shunned by the public. Because the greater part of society still holds this ancient attitude, the victims are subjected to immense grief and suffering. This attitude is not justified nowadays, yet it is often the reason why persons with leprosy are segregated from society or compelled to live in isolation, and therefore in need of social assistance.

The two main classes of leprosy cases are: (*a*) the "open," or bacteriologically-positive class, comprising mainly the lepromatous type; and (*b*) the "closed" or bacteriologically-negative class, this being mainly the tuberculoid type. The distinction is important because, in the light of present knowledge, it is the bacteriologically-positive class that is considered contagious and dangerous to the public, whereas persons with bacteriologically-negative leprosy are generally considered not dangerous to healthy persons in their environment.

In the antileprosy campaign there are two main lines of activity:

1. The rendering of medical or physical care or treatment. The primary aim of medical treatment is to overcome the infection, so that the patient may no longer be a source of infection of healthy people in his environment.

2. The rendering of help to assist the patient to return to normal

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social life. These duties are the essence of what is called social care. They vary according to where the patient is and what he can do, and this problem is the subject of the following discussion.

1. *Patients segregated in a leprosarium.*—Although only infectious (bacteriologically positive) cases require segregation, this measure has not yet been brought into effect throughout all of Indonesia. There are still many such persons living in the *kampongs* (community settlements), unable to earn a living because of the attitude toward them of the people of their communities.

Unlike ordinary sick people in general hospitals, who generally require treatment for relatively short periods, the leprosy patients, who are often well enough to entertain normal desires but usually require prolonged treatment, also need mental care. Since the general health is ordinarily not affected, the patients in a leprosarium should be allowed to live among their fellow patients as nearly as possible as they would in their own communities if healthy, so that after recovery and discharge there will be no difficulty of readjusting to their normal way of life. To that end the following program should be carried out in each institution.

(*a*) Occupational facilities: Occupational therapy not only helps to maintain or restore the physique, but is also conducive to a wholesome state of mind. The patient should feel that he is a full-value member of society who only requires temporary hospitalization, with the expectation of returning to his native village. According to his ability and capacity, each patient should be given the opportunity to practice a trade, such as shoemaking, carpentry, tailoring, weaving, etc. Farming and like occupations should also be encouraged.

(*b*) Education: For the children, public schools should be set up to enable them to continue their studies at ordinary schools outside after recovery. Illiterate adults should be taught to read and write. Besides general subjects, popular improved methods of agriculture, stock-breeding, and craftsmanship of various kinds should be taught. It is also important that the patients be taught in a popular way something about hygiene and dietetics, and especially about the modern concepts of leprosy and its treatment. This would be of great value for their mental well-being, giving them faith in their recovery, and it might also provide useful workers for the campaign against leprosy.

(*c*) Recreation: Facilities for entertainment and recreation should be made available, including reading rooms and provisions for theatrical plays, music, chess and the like. Cinema shows of films of an educational nature are of value.

(*d*) Religion: All patients should be given the opportunity to practice their own religions. Each leprosarium should have a small house of worship (*langgar*) or mosque (*mesdjid*) for those who profess the Islamic religion, and where needed suitable places for Christians and Buddhists. Religious teaching is a factor of great importance to the patients, and

an excellent mental remedy for those who are depressed by the fear that their ailment is incurable, that they are condemned by God and forever severed from society. With improvement of their spirits, and faith that God will aid in their recovery, the medicines employed become more effective.

(*e*) Physical training: Physical training, combined with the medical treatment, may prevent or alleviate the deformities of leprosy. Sports should be organized under expert guidance, especially among the children.

2. *Patients living in their home communities.*—Although bacteriologically positive cases require segregation, that cannot always be accomplished. Many such persons are heads of families and object to seeking admission in an institution because of lack of social provision for families left behind. Society should realize that when a patient enters a leprosarium a source of infection has been removed from the community, that he has sacrificed himself with respect to his family, possessions and property. Society, therefore, has a moral duty to render socio-economic assistance to the family.

Another class of persons who require assistance are the bacteriologically positive patients who are unwilling to leave their relatives and go to a leprosarium. These people—at least in Indonesia—usually live in isolation, sometimes because of pressure of community opinion and sometimes because of the propaganda of the leprosy service. They may live in rooms by themselves, or in separate habitations. Many of them are unable to earn their daily living. Such people obviously need social help when their families or other entities cannot provide for them; otherwise they are compelled to wander about begging for alms, visiting marketplaces, shops and other crowded places. Making such contacts with other people, they are a certain danger of infection, particularly to children.

3. *Rehabilitation.*—The problem of rehabilitation of leprosy patients arises from two things: first, the persisting prejudice which makes it extremely difficult for them to return to and live in society in a normal way, although of good will and physically capable of carrying on with their former occupations; and, second, because of the after-effects of the disease when, because of late treatment, there are deformities which make them incapable of resuming the work they used to do.

What are the aims of rehabilitation of leprosy patients? For those who have recovered clinically—arrested cases—there is no longer any reason for them to remain in an institution, and therefore they are allowed to return to society; and they should be accepted by the community and be given a chance to work. Rehabilitation of these ex-patients should concern not only their physique (i. e., restoration of deformities) but also —and even more important—their mentality. As Jagadisan, organizing secretary of Hind Kusht Nivaran Sangh (Indian Leprosy Association) has said (1):

> Rehabilitation is not mere physical restoration attended by economic sufficiency in an environment which is removed from normal society. Rehabilitation is Restoration to Normal Life.

It is heartening that in Indonesia a change for the better is noticeable in this respect, because of the educational campaign of the Leprosy Control Service. Quite a number of leprosy patients have been allowed to continue their work in the government services and in private enterprises while under medical treatment. Also, school-children with "closed" leprosy are at present allowed to attend school, with due observance of the existing government regulations.

There are at present, in several countries, two forms of rehabilitation of leprosy patients:

(*a*) In the leprosarium: In this country, connected with a hospital to which leprosy patients can be admitted for treatment, there is a rehabilitation settlement where able-bodied ex-patients are given the opportunity to work and thus remain physically fit. This sort of arrangement, however, is only the first stage towards full rehabilitation, *i. e.*, restoration to normal life. The patients' minds are not rehabilitated, for they still consider themselves belonging to the category of sick people.

Here lies an important task. The more the general public is enlightened about the true nature of the disease, the greater will be the number of clinically cured patients to be accepted by their native villages.

Perry Burgess, who was chairman of the Committee on Social Aspects at the Madrid congress (2), has said (personal communication):

> I am no longer so enthusiastic about my idea of colonies because, considering the over-all picture, it might only serve to increase the danger of deepening public ignorance, fear and prejudice.

This is quite so. In Madras, for instance, although in the orthopedic and plastic surgery department of a leprosy colony headed by Brand, operations are performed to relieve or improve deformities, the community is still hesitant to associate freely with the ex-patients. As long as society persists in this attitude, ex-patients will always be unhappy and have a feeling of inferiority. They may indeed have been rehabilitated physically, but certainly not mentally.

(*b*) In special institutions for ex-patients: In such places only arrested cases are admitted, both those able to work and those unable to do so, and they should be given occupations according to their individual capability. Such a colony for instance, is to be found in the Philippines, the so-called "Negative Barrio" (village) at Cebu under the Social Welfare Administration. Although these ex-patients are removed from the leprosy hospital, in reality they are still segregated from normal society-association, and that is likely to lower their morale. This is the second stage of restoration to normal life.

The third stage is to remove the feeling of being segregated from healthy people. This could best be accomplished by allowing these ex-

patients to work together with healthy workers from neighboring villages, for instance in the cultivation of gardens or rice fields. In Indonesia experience of this kind was gained by Gramberg at the Donorodjo leprosarium near Semarang before World War II. A similar scheme has recently been advocated by Jagadisan (1), who wrote:

> I would plead that all such colonies must be very small ones and should include quite a few who have not had leprosy so that the stigma of a specialised colony may not be attached to them.

This of course would depend on the circumstances in each country.

The fourth stage of rehabilitation will be reached when the ex-patients are allowed to return to society. It is of course possible to speed up the progression from one stage to another, but this will depend on the attitude of the public at each place. Under favorable conditions a negative patient discharged from a leprosarium could return directly to his former community.

The present situation in Indonesia is that many arrested cases are working in leprosy colonies, and a small number have been accepted back by their communities, no longer dreaded. It is hoped that gradually, through education of the general public, more ex-patients will be integrated until finally there will no longer be need of centers of interception between the leprosaria and the healthy community.

4. *Preventorium.*—It is generally accepted that the spread of leprosy is caused largely by its infectiousness for children. Adults in general are not easily infected, whereas young children of leprous parents are very liable to be infected. Children are an important factor in leprosy control, not only because of their susceptibility to the disease but also because leprous children are an even more dangerous source of infection than adults: they will play with healthy chidren, and the chances of transmitting the infection are high.

In Indonesia, special attention has long been paid to child leprosy. Among other things, at the instigation and under the supervision of Sitanala, Soetomo and Soetopo (4, 5), a special home was set up in Gresik (Surabaya) for the care and treatment of children with leprosy.

Of late years it has been recognized as important to take care that the healthy children are not infected by their sick parents. The preventive measures we aim at are: 1. A baby born to a leprous mother should be removed from contact immediately at birth. 2. Children of leprous parents who show no signs of leprosy should be taken care of in a children's home, called a preventorium. These measures of course pertain only to mothers with an infectious, or "open," form of the disease.

Babies and young children in a preventorium naturally require proper and expert care. At the Culion leprosarium in the Philippines, which I visited in 1953, there is a preventorium, or nursery, for about 50 infants born in the colony of leprous mothers, from whom they are removed at birth. In charge of this nursery is a lady doctor, a pediatrician; and the

children are looked after by Sisters of St. Paul de Chartres, assisted by a number of healthy girls in training. All the children there undergo repeated lepromin testing, and those who do not become strongly reactive are vaccinated with BCG. Because of the limited capacity of the nursery it is necessary that children who are not taken away by healthy relatives by the time they are four or five years old (and very few are claimed by outside relatives), are returned to their parents in the colony. It is expected that the immunization they have received will protect them from infection. There are also a number of older Culion-born children in an institution in Manila under the Social Welfare Administration, where they are supposed to receive education and practical training to facilitate their taking care of themselves in the outside world later on.

In Brazil, preventive care for children of leprous parents is provided for on a large scale, 27 preventoria with accommodations for 5,000 having been established. In India, according to Muir (3), 750 such children are taken care of in preventoria supported by the Mission to Lepers. He estimates that the number of infants and children exposed to infection by their parents in that country is more than 15,000.

We in Indonesia have plans for the establishment of a number of preventoria, one of which, connected with the leprosarium at Tangerang, West Java, will probably be completed this year. The existing preventorium near the leprosarium at Pelantungan, in Central Java, has been in use since 1930. As a rule the children born to leprous mothers are given, with the usually reluctant consent of their parents, to healthy relatives, or placed in an orphanage, or turned over to the Salvation Army to be taken care of.

Important factors in this connection are the difficulties met in attracting social workers sufficiently interested to work in this field, and in arousing in the parents sufficient understanding for them to realize the necessity of cooperating with the doctors and social workers. This understanding can of course be imparted only through education and enlightenment.

There are many social aspects connected with the problem of preventive care, and we must give our best endeavors to arousing the interest of social service organizations, in particular the women's associations, to give careful consideration to the alleviation of the fate of thousands of infants and children in our country who are now exposed to infection by their leprous parents.

SUMMARY

1. In the control of leprosy the social care of patients and their dependents must be regarded as of primary importance.

2. Social assistance must be given to patients because, (*a*) the public still fears people with leprosy so that they are not tolerated in the community, thus compelling them to be segregated; and (*b*) the after-effects of the disease often render them incapable of earning a livelihood.

3. Social care should be given to a patient's family when he is the bread-winner and has to enter a leprosarium.

4. Persons with leprosy require mental as well as physical rehabilitation. Mental rehabilitation requires the enlightenment of the public so that they will adopt a reasonable attitude toward persons with leprosy and permit them to live normal lives. Physical rehabilitation requires several forms of care, including the services of specialists in orthopedic and plastic surgery.

5. Because leprosy is an infectious disease to which young children are particularly susceptible, the establishment of preventoria is a part of the campaign against the disease. Babies born to leprous parents, and infants who have had contact with leprosy patients, should be admitted to such institutions.

6. Inoculations with BCG should be carried out on children who have had contacts with leprosy patients.

RESUMEN

1. En la lucha contra la lepra hay que considerar la asistencia social de los enfermos y de sus allegados como de importancia primordial.

2. Hay que suministrar asistencia social a los enfermos porque: (*a*) el público todavía abriga temor a los leprosos y, por no tolerarlos en la colectividad, los obliga a mantenerse segregados; y (*b*) las secuelas de la dolencia los incapacita a menudo para ganarse la vida.

3. Hay que facilitar asistencia social a la familia de un enfermo cuando éste es el que sostiene el hogar y tiene que ingresar en una leprosería.

4. Los leprosos requieren rehabilitación psíquica así como física. La rehabilitación psíquica requiere la ilustración del público a fin de que adopte una actitud racional hacia los leprosos y les permita llevar una vida normal. La rehabilitación física requiere varias formas de asistencia, incluso los servicios de especialistas en cirugía ortopédica y plástica.

5. Por ser la lepra una enfermedad infecciosa a la que son en particular susceptibles los niños pequeños, el establecimiento de preventorios forma parte de la campaña contra la dolencia. Los hijos de leprosos, y los lactantes que han estado contacto con leprosos, deben ser recibidos en esas instituciones.

6. Deben llevarse a cabo inoculaciones con BCG en los niños que han tenido contacto con leprosos.

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