

### **Social factors operating against effective leprosy control in the highlands of Papua New Guinea(\*)**

J. M. KERR (\*\*)

Western influences have succeeded in changing much of the traditional outlook towards leprosy which was not one of condemnation or ostracism whilst a patient could adequately perform his obligations to his society.

Introduced medical services to leprosy patients must frequently appear to be ineffective to the Papua New Guinean and these services have often caused considerable disruption to and isolation of patients, resulting in numerous social difficulties. Additionally the sophisticated, educated Papua New Guinean has come to know and express in many instances, attitudes; of fear and ostracism, which surround the disease in so many other parts of the world.

Such factors often hamper attempts to provide better leprosy services in the Highlands area.

In a country where traditionally leprosy is viewed rather fatalistically as an integral part of the health hazard, and where considerable faith is held in the effectiveness of traditional cures, Western influence has introduced additional social factors which operate against effective leprosy control measures.

Pre-literate man inevitably turns to the super-natural for an explanation for many of the hazards encountered by him and this is particularly so in regard to disease. Leprosy, which appears to strike haphazardly, is chronic in nature and can result in much disability, is explained by the Papua New Guinea villager as a supernatural phenomenon. He considers that leprosy results either from spiritual retribution for some transgression against the laws or mores of his society, or as a direct result of sorcery worked against him by an enemy.

Leprosy is readily recognized even in its early stages and various attempts, ranging from scarification of lesions to patient killing and offerings as rituals of appeasement were made to rid patients of the disease. Probably due to an occasional natural self-healing case, some of these attempts would be considered as being successful appeasement practices.

The leprosy patient in the village is normally not an object of fear or scorn, and most patients pursue their usual activities without any adverse social or economic effects. Due to lack of manual dexterity required among rural dwellers, even minor

(\*) Reprinted with permission from Papua New Guinea Medical Journal 16(2):118-120, 1973.

(\*\*) Miss J. M. Kerr, Social Welfare Officer, Regional Leprosy Control Unit, Mount Hagen, Western Highlands District.

disabilities will present no physical problem to patients.

It is only two types of patient which generate anxiety amongst the healthy — the burnt out tuberculoid and the advanced lepromatous, where immobility, dependence and deformity are factors. These patients are regarded as being possessed by evil spirits and represent a danger to others. They were traditionally disposed of by burying or by throwing the bodies into a turbulent stream, generally prior to death. Fear of contagion is not thought to be a factor, rather fear of the evil spirits entering the body of another person.

Unless the patient became so ill or useless as to contribute nothing he then had a reasonable chance of remaining happily in his society, and some "success" in traditional cures would reinforce the patient's optimism for overcoming his affliction. In most cases then the patient is not at any great disadvantage because of the disease, and is probably not greatly motivated to seek out European medicine and assistance.

These attributes are probably further supported by the effects of a Western leprosy control programme which may also deter the patient from seeking treatment in several ways.

A major source of dissatisfaction and concern amongst patients is the period of hospitalization frequently required for both infectious and limb damaged patients. Policy until 1958 was for the isolation of all known patients, often in hospitals in foreign areas, and although the emphasis now is on domiciliary treatment where possible, there remains a tendency for patients to hide, avoiding both detection and enforced isolation from their community.

Patients are justifiably anxious about being sent to a foreign area amongst strange, unknown people for a period of years. Probably of greater concern to the patient, is the social and economic loss that he will suffer over this period. Regardless of his

background, whether he be an uneducated subsistence farmer or an educated urban worker, hospitalization must appear to him as his social and economic downfall. Due to his non-participation in his society he stands to lose all his rights and privileges simply because of his inability to carry out his obligations to his society; for example his failure to utilize his clan land may lose him later rights over the land. A sophisticated patient may be forced to give up the job for which he has been trained, and possibly legislation may prevent him from a resuming this type of employment for the rest of his life.

The hardships imposed by long term hospitalization, although not always as obvious as lost wages or employment, are felt by most inpatients, whether it involves a reduction of bride wealth for a young female patient of marriageable age, or the loss of home and familial ties and the subsequent breakups of traditional marriages and family groups. The enforced isolation of an individual from his family is a real source of social problems amongst patients.

The medical and surgical efforts which we so often regard as successful must often appear to the patient as insufficient justification for long term isolation in light of the problems he faces as a result. The success of Western medicine in treating leprosy must be somewhat unimpressive in the eyes of the average Papua New Guinean.

Considerable success and appreciation has been seen in Papua New Guinea in the treatment of acute conditions with quick, effective Western cures. Leprosy, however, demanding long term prolonged drug therapy and continual care and vigilance against limb damage and deformity would hardly rate a similar respect.

The prospect of taking medicine for years where no radical improvement or change is apparent in one's condition would hardly arouse interest in our own society, let alone be of concern to a Papua New Guinean to

whom it is abstract and intangible. The drug becomes less effective in his eyes too, when it fails to prevent ulcers on his feet or the contraction of his fingers, an idea not so ridiculous to him, if he does not fully comprehend the reasons for the medication.

Similarly, if he is not sufficiently motivated to exercise surgically regained function in his limbs or to care for healed ulcers, contractures and ulcers will recur, leaving him more doubtful of the ability of Western medicine to adequately meet his needs. He may well consider that the social loss imposed on him by his isolation is hardly warranted for the lack of improvement apparent to him, and he may also consider that his chances with traditional cures or methods of appeasement are equally as good, without the social and economic disadvantages brought about by Western methods.

Admittedly the majority of patients do not require in-patient treatment and are not isolated from their society, the only imposition being that they must obtain treatment regularly from their rural centre. For reasons mentioned above, the effort may not be considered worthwhile, so insufficient treatment will lead to a worsening of the condition, but this too could be interpreted as the ineffectivity of Western medicine, rather than the patient's own fault. The interest and care given to the majority of patients on a domiciliary basis is often lacking and not encouraging for the patient to seek adequate treatment and even where drug treatment is regularly obtained, ulcers and deformities may be allowed to develop unnoticed or ignored. Unfortunately, this is a problem of a developing country where a relatively small proportion of financial and manpower resources are available for such a specialist function, and much of the responsibility for patient care is delegated to rural health workers, where possibly ignorance and disinterest in leprosy patients amongst a wealth of other, more urgent, medical problems prevails.

The obvious failures from both institutional and domiciliary care centres serve only to reinforce the spiritual aspect of the disease, due to the European's failure to deal with it adequately with his medicines.

In the traditional sphere there are many factors operating to deter patients from seeking treatment, but Western influence has introduced another foreign concept which deters particularly the sophisticated patients, who may otherwise have readily sought treatment. This is social ostracism against patients which is becoming increasingly apparent with social change in the Highlands. It has been observed in many other developing countries that numerous social barriers are placed against patients in the middle and upper social strata, while the lower strata accept the disease with fatalism. This trend is now apparent in Papua New Guinea, and can be observed among patients who, for example, have difficulty in obtaining work, may be rejected as a marriage partner, or face exclusion in many social situations where fear of the disease affects acceptance of the patient.

Fear and concern that their peers will learn of their illness is obvious amongst many of our sophisticated patients now, suggesting that we have succeeded in teaching the population that leprosy is infectious but not that it can be cured. Such attitudes further encourage concealment of the disease among even the enlightened section of the population. The biblical idea of leprosy as "loathsome" and the ignorance of many Europeans in regard to the nature of the disease have both helped to encourage and increase the stigma of leprosy present in numerous other countries, and now in Papua New Guinea.

Various social factors, some introduced from Western culture, certainly operate against effective leprosy control measures. The factors outlined above are sufficient to deter many patients from seeking early treatment and the delay assists in creating many of the problems faced by leprosy pa-

tients. The extent to which traditional factors alone operate is not clear, however it is apparent in certain areas where hospitalization is not a factor, and where regular and supervised control measures have brought about general and obvious improvement among patients, that traditional attitudes toward the disease still encourage avoidance of detection.

This would suggest even where many of the newer social factors mentioned are overcome and control methods are conducive to full co-operation by avoiding disruption to, and isolation of, the patient, tradi-

tional beliefs and attitudes engender a certain reluctance to utilize Western methods in the treatment of leprosy. Only with more extensive health education on the nature of leprosy and possible problems arising from it, and a concerted effort to improve the attention and service given to patients, will many of these problems and prejudices be overcome. This may not only assist in reducing many of the physical and economic hardships placed on patients, but could alleviate much of the fast growing social stigma surrounding leprosy in a society where no such stigma previously existed.