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PSYCHOLOGICAL ASPECTS OF LEPROSY

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Leprosy is unique among infective diseases in the intensity and persistence of its emotional content. Every leprosy patient is a person under stress, and the doctor's acceptance of this and sympathetic reaction to it underlie any success we may achieve in dealing with this disease. The psychological aspects of leprosy thus need to be thought of in relation both to the patient and the doctor himself.

The Patient

Stress in the leprosy patient derives from 3 main sources.

1. *The stress of inherited ideas.*

It is of profound importance for the health and wellbeing of most people that they should be accepted by their fellows and play their part in their community. Without this there is no enduring happiness or fulfilment, and rejection by the community is the ultimate calamity. Long ago in the history of mankind a group of conditions was identified which merited such rejection. These were of two sorts. One was criminal conduct which threatened the structure of society. The other was disease which seriously threatened the life of others either at the physical or spiritual level. Leprosy, with its mysterious origin, long course and disfiguring disabling effects became one of the most dreaded of these conditions.

Born into the community, we inherit its social and religious ideas. In spite of the scientific evidence, ancient fears and prejudices regarding leprosy are extraordinarily ingrained and persistent, even in the most sophisticated societies. They invariably associate leprosy with ideas of guilt, rejection and isolation, so that even before he develops any symptoms the patient may be conditioned to anxiety by the very thought of leprosy, and the first suspicious symptoms may cause an acute emotional disturbance. I have encountered patients who burst into tears when told with the greatest discretion that they had leprosy, and equally others who burst into tears of relief when told they had no sign of it. The psychological trauma is thus there at the outset, conditioned by social attitudes and ideas. Its practical result is all too often the feeling that the disease must be concealed. For many a patient it requires no small amount of courage even to consult the doctor, and he comes fearing the worst.

2. *The stressful experience of leprosy*

The more one considers what it must feel like to suffer from leprosy, the more obvious is it that here is a disease which in its most common and ordinary manifestations is highly productive of psychological stress.

(a) *Facial lesions.* The frequency with which most of us look in a mirror is sufficient evidence of the importance society places on facial appearance. Facial

disfigurement, whether through unsightly patches, infiltration or paralysis is always an important source of anxiety, but there is one condition par excellence which experience has shown matters more than any other, and that is collapse of the nose, because this is thought to be pathognomonic of leprosy. In India patients often kept completely silent about their nasal symptoms because their anxiety regarding them was so acute, and only matched by their gratitude when the doctor showed his concern and initiated treatment.

(a) *Living with anaesthetic limbs.* The constant experience of numbness of the hands and feet, maybe for years on end, is inevitably stressful, while its attendant risks of burns and injuries must be a perpetual source of frustration and irritation. It is easy to tell the patient that his hands and feet are at risk, that he must inspect them daily, wear suitable footwear always, avoid handling hot cups, sharp instruments and so on. It is quite another thing for the average person to have his mind so concentrated on these things that he faithfully carries them out. Would we? For ordinary people lapses are inevitable in the demands of everyday life, with their equally inevitable results, but psychologically the cold insensitive hands and feet are themselves a sufficient cause of stress.

(c) *The impact of paralysis.* Paralysis of muscles occurs in other diseases. The peculiarly stressful element in leprosy arises from the selection of muscles involved, especially in the hands, and the manner in which this affects daily living. Loss of the capacity for delicate movements may have profound consequences where work is concerned. Equally profound is the effect on self respect when one becomes unable to wash oneself properly, do up buttons or tie the string of one's pants. These are common disabilities in leprosy.

(d) *Disturbances of sweating.* Loss of the capacity for sweating in one part of the body must be compensated for by increased sweating elsewhere. One of the common embarrassments of leprosy is the excessive sweating of face and trunk, and nothing can be done about this. At the same time, while hydrotherapy and oil massage may counteract the all too common dryness and tendency to cracking of the skin of the feet, here is another daily chore to make life burdensome.

(e) *Involvement of the genitalia.* This is very frequent in male patients with lepromatous leprosy, and a potent cause for the break-up of marital relationships. Even more than the nose, this is an aspect of his trouble about which the patient feels so strongly that he often does not mention it. Specific reference to it in the privacy of the consulting room often led patients in India to expose nodules on the scrotum or prepuce, with the opportunity for reassurance and comfort, occasionally backed up by minor surgery.

It is the cumulative effect of these various symptoms which gives leprosy its peculiar nature as a source of stress. When we add to them the eye complications, the reactive episodes, even the subtle odour which may accompany the disease when severe, we have here a situation unique in medicine.

3. *Stress in home and family life*

Yet a third area of stress arises from the destructive impact of the actual disease on home and family life.

One aspect of this is the threat of unemployment, always present as a result of social attitudes, but becoming really dangerous when work efficiency is impaired.

Within the family circle profound problems arise in relation to marriage. If the patient is a woman, in many societies she will be fortunate if her husband does not divorce her. If the patient is a young man engaged to be married, not only is his own marriage likely to be cancelled, but his unfortunate sisters may be

condemned to spinsterhood. The termination of sexual relationships between husband and wife is common in India, not only at the demand of the spouse, but frequently of the patient's own choice. It is widely believed that children are especially susceptible to leprosy, and acute anxiety regarding the children living in the house is almost commonplace.

Every patient who comes to us with leprosy, however early, is thus the target of stress from many angles. The result is all too commonly a depressive mental state. This is important, because it may affect the ability of a patient to respond in a normal responsible way to the advice of the leprologist, whether in relation to chemotherapy, hand and foot care, or cooperation in leprosy control measures. One encounters patients who regardless of the advice given, take in their anxiety one form of treatment after another, often in highly unsuitable dosage, and thereby provoke persistent reactive phases. In others, apathy leads to failure to take prescribed treatment, neglect of exercise, and loss of the will to recover.

Practical Measures

The first requirement in the response of the doctor is to see the patient in the light of his difficulties and receive him in a manner which convinces him that to us at any rate he is a person no different from other people. This involves courtesy, understanding and patience in all dealings with him, privacy in examination, the same levels of medical care as other patients expect from us. His cure begins with our acceptance of him as he is.

2. We shall offer him our professional skill, and there is no need for further reference to this. At the same time a positive attitude on our part to encourage his confidence and the sharing of his anxieties with us will certainly mean that he will return again and again and increasingly offer his cooperation and loyalty. At a leprosy hospital known to me, 70% of the numerous new patients come on the recommendation of old patients.

3. The sympathetic investigation of the patient's mode of life will often reveal contributory factors in persistent reactive phases and be of direct clinical importance. The alleviation of such factors may not be difficult and may lead to dramatic improvement also in his mental condition. A welfare or social worker is an essential member of the healing team.

4. The question of approach is particularly important in a leprosy control programme. It is not enough to provide facilities for DDS treatment somewhere within reach of the patient without going into the question as to whether he can actually avail himself of them. Control methods must be adapted to the actual situation of patients. As Kinnear Brown (1960) put it, "The outcome of the mass campaigns depends on the integrity, personality and assiduity of each individual participant, and on the confidence engendered in each patient that he is regarded and treated as an individual, and not just as another member of a milling crowd or an elongated weekly queue". The patient regularly taking DDS is a patriotic citizen and deserves to be treated as such.

5. Most important of all in the long term is the need for much greater emphasis on the leprosy education of the public as a deliberate policy. The facts do NOT speak for themselves. Only when continually re-iterated are they likely to have any impact on a conservative society, and produce that change of heart which alone will save the leprosy sufferer from his anxieties.

The Doctor Himself

Finally, what of ourselves in relation to leprosy, the doctor no less than his patients inherits the ideas of his community, and 6 years of medical training may not suffice to eradicate deep seated fears and prejudices. Visiting a young colleague at his clinic one day rather unexpectedly I found that it was his practice to sit at a table at one end of a large room with his register in front of him, while patients filed past at the other end of the room and received their DDS from a patient assistant. This was as near as he ever got to his patients, and there was no need to enquire further as to the cause of poor attendance and a general air of depression.

Success in leprology depends first on the doctor coming to terms with himself. We know that we and those who work with us are exposed more than most to infection with *Mycobacterium leprae.* We also know better than most the full range of facts about the transmission of *Myco. leprae* and can take appropriate precautions. Leprosy is surprisingly rare among workers at leprosy institutions. A positive lepromin reaction is reassuring. It can often be induced by repeated testing or by BCG. If confidence is still lacking, there is still the possibility of chemoprophylaxis. In the exceedingly unlikely event of the doctor catching the disease, the certainty of very early diagnosis and competent treatment with no lasting stigmata should suffice to rob both the disease and any fear of it of any sting.

The disappearance of secret fears and inhibitions opens for us a world of service to our patients, which for them means an available and reliable friend and adviser; and for the doctor the deep satisfaction of involvement in the battle against one of mankind's ancient and most intractable enemies.

Reference

Brown, J. A. Kinnear. (1960). Mass campaigns and the individual. *Lepr. Rev.* **31**, 19.