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Psychologic Difficulties in the Treatment of Leprosy Patients in a Nonendemic Country

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The views presented here are not the result of statistical evaluations. To make these, the number of patients we treated in Germany would have been too small. We should, nevertheless, like to try to draw conclusions from some observations.

At present ten patients are being treated in our hospital, and two of them are being admitted to it. We are still in contact with two discharged patients who have gone abroad. Of our patients two are Indian, two Indonesian, two Italian, one Jordanian, one Turkish, one Spanish, one stateless, originating from a Baltic country, one West African and one German. Two are women. The majority of the patients suffer from the lepromatous or the borderline-type of leprosy, with lesions which are or have been readily visible when the patient is normally dressed. Only one patient is severely crippled in hands and feet. With the exception of the one German patient (now working abroad), and two patients who could be described (somewhat unkindly) as "social flotsam," all our patients are foreign laborers or students who intended to live in the Federal Republic for several years. These people always and naturally have difficulty in adapting themselves. They remain "strangers," often mentally shaped by their ambivalent feelings about their surroundings. In this situation illness means a threat to the already labile equilibrium. If the diagnosis is "leprosy" the disturbance of the equilibrium is almost predictable. In nearly all the cases we have observed that communication of the diagnosis caused a crisis. Some examples follow:

An Indonesian patient was sent to us by a colleague for further consultation. He was one of the few patients with the tuberculoid type of leprosy. No signs of the disease were visible at first sight. He often had business abroad, though he lived in Indonesia. When he consulted us, he told us that he had "given up life for at least some years." He was convinced that his professional and marital life had come to an end, saying "I have to start anew at the very bottom." When we explained to him that he could carry on his normal life, without any alterations in his professional or familial relations, it took a week of solitary holiday for him to become accustomed to that new situation!

A patient from Jordan was sent to us under semi-police-guard. We thought that he was in real danger of suicide. After two days in our hospital this attitude changed into one of aggression against the nurses and doctors. After some time this diminished, when the first signs of healing appeared.

An Italian patient spent the first week in our hospital crying and sleeping. He could not believe in any possibility of improvement for his illness, which in the beginning rather disfigured his face.

We observed such reactions in all our patients after they had been told the diagnosis—though not always as outspokenly as in these examples. Of course this reaction is not unknown in endemic countries. One of us has seen two cases of suicide in young Indonesian women after they had been told they were suffering from leprosy. But this desperate attitude is not a very general one in endemic countries; that we encountered it in all our patients may well have been connected with their particular positions. As strangers they were suddenly confronted with a chronic disease, which—at least in their view—caused immediate interruption of their studies or earnings. In this respect their situation is not different from that of patients suffering from any other chronic disease. However, there are two other psychologic factors, typical for

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leprosy, which must be added: the concept the patient has of leprosy and the ideas prevalent in his environment.

The concept of the patient himself about leprosy, in all our patients when we saw them for the first time, was unrealistic. In the beginning all of them thought their situation was "catastrophic," "hopeless" or "desperate." In one Italian and in the Jordanian foreign laborer that feeling which O. K. Skinsnes has described as "Lepra-Angst" could be clearly recognized. Especially the Italian saw his illness as "God's punishment." He could not, however, relate the "justice" of this "punishment" with moral faults he was aware of.

Likewise *the ideas of leprosy prevalent in the surroundings of the patient* are usually unrealistic. Particularly, two false concepts we meet again and again: that the disease is incurable and that it is extremely infective. In addition, among Christian groups it is sometimes thought that leprosy is a disease which must be considered as a particular curse. These false concepts are not limited to "the common man." Once we were consulted by telephone by a desperate colleague who had discovered that one of his children had shaken hands with a (bacterioscopically negative!) patient. The medical director of a medical service once consulted us to get information about the disinfection of an ambulance in which a (cured!) leprosy patient had been transported.

This medical malinformation can be cured relatively easily. It will be much more difficult to change the ideas of the majority of people. In any case it will be necessary for the leprosy relief organizations to give up fund-raising by means of "horror-pictures." Successes in fund-raising can too easily be obtained by confining oneself to therapeutic possibilities. It must be possible to promote the much more important prevention of the disease to the main theme for fund-raising. Surely this would have influence on the image of leprosy in the eyes of the public.

Further complicating factors with psychologic consequences for patients are medical mistakes. In general in a nonendemic country the process of making the right diagnosis is a very long one, even in quite typical cases. In our patients we saw the following wrong diagnoses: rheumatism with drug allergy, urticaria, sarcoidosis, tuberculosis of the skin, and warts. In all cases those led to postponement of the beginning of the right therapy. In three cases it was probably the therapy based on the wrong diagnosis that led to a severe reaction. Once a threatening situation was created by mistaking the dosage-scheme of sulfa drugs for that of sulfones. After the administration of four grams of diphenylsulfone in one day a reaction occurred, which made the patient despair of the possibilities of therapy for his illness. Once the Cushing-syndrome arose in a patient whose illness was rightly diagnosed as "lepromatous leprosy in reaction," and who was treated with corticosteroids for a long period. This patient, too, had great difficulty in believing in the possibility of being cured. It is remarkable that three of our patients knew from what they were suffering, before the doctors could make the right diagnosis. In these patients quite an amount of mistrust had to be overcome. This was especially so when our therapy differed from one which had been applied before.

Another cause of psychologic difficulties in the beginning of the disease is the *isolation* of the patient. In none of our patients have we practiced strict medical isolation. Nevertheless some form of separation from other takes place in nearly every patient. He has a secret to keep from nearly everybody: his illness. Communication of this secret to "others" would, in the opinion of the patient, at once cause his nearly absolute isolation—and most probably this opinion is right. He cannot tell stories about his symptoms, progress and drawbacks, as other patients in the hospital often do with obvious delight. By this reluctancy he isolates himself, no matter how little "administrative" isolation may be forced upon him. The difficulty remains during a long period of his treatment; it ceases only when the patient has been discharged from hospital. It can even return more forcibly when resettlement in a normal life has to take place. The reintegration of one of our patients failed, because the "facade"-diagnosis, "allergy against machine oil," was not accepted by his fellow factory workers. The

"secret" illness was denoted by them as "Aussatz" (the biblical expression used in German for the translation of "zara'ath," a word which has clear overtones of horror, isolation and curse). This led to an isolation by the factory workers, which in its form came near the biblical practice against "zara'ath."

Very severe depressive symptoms lasting a week were shown by one of our patients after the "demonstration" of his case in a university lecture. A complete "encapsulation" from the surrounding world took place; for hours on end the man lay crying in his bed. Constantly he repeated: "I'm a man, I'm not a dog." Also the examination for leprosy in a more or less public serial procedure has caused much offense in one of our patients. He maintained that this form of examination of his colleagues would close the factory definitely to him after his discharge—and he has been right.

When *reactions* occurred, we had always to cope with more or less severe depression-like anxiety states or states of excitation. Usually these states reacted well on treatment with chlordiazepoxide (Librium). In some of our patients, who were no longer in the active initial stage of the disease, it was remarkable how important psychologic factors were in causing reactions. Once we could observe exactly in one of the patients the generation of erythema nodosum leprosum in the course of one day, during which the patient had to cope with an ever increasing psychologic stress. This occurred one day before Christmas, when the patient wanted to phone his Italian family from Germany and the connection could not be made, despite hourly attempts. The same patient is well aware that positive or negative deviations from his psychologic equilibrium easily cause reactions: "I sweat my disease," he said. We have the impression that especially in reactions which have been "caused" in this way, thalidomide has a very rapid beneficial action.

After the apathy or the revolt against the surroundings of the first weeks or days had been overcome, the majority of our patients developed an exaggerated strong bond with those treating them. The bond mostly took the form of a strong feeling of dependency, which, of course, was further enhanced by the often rather spectacular successes of the treatment. One foreign laborer among our patients said to his doctor, "You are my God," a student said: "I owe you my life."

It seems to us that one has to reduce this abnormally strong feeling of dependency by developing the patient's own possibilities. During the stay in hospital, this can be done only by occupational therapy, by continuing studies which had been taken up before the disease broke out, or by starting into a new field of studies. It is probably significant that successful therapy and at least somewhat successful reintegration of our patients has always correlated with the desire for occupation at an early stage of treatment in the hospital. For the occupational treatment needed, the hospital, unfortunately, is the least suitable place one can think of. In our opinion it is of paramount importance, therefore, to discharge a patient as early as by any means possible. Many reactional phases can be treated ambulatorily, when they occur; short periods of hospitalization suffice for the more serious cases. In two of our patients (designated above as "social flotsam") reintegration has not succeeded up till now—and the possibilities for the future seem to be very small indeed or none at all.

In our opinion a patient who wants to return to his country should not be discouraged from doing so. No doubt problems can arise when, in the patient's home country, strong prejudices against leprosy still exist. In some of our patients (two Indians, one Italian and one Spaniard) the fear of return —especially to the surroundings of the patient's family—was considerable.

After the period of the first shock is over, and when the patient starts hoping again, new psychologic difficulties sometimes occur. In eight of our patients in this period tensions in the sexual sphere became obvious. Men became anxious about their sexual potency, and one woman about her fertility. In this period many patients became impatient with the progress of therapy, which they have by now recognized to be slow. With one of our student patients we had to have talks for hours to convince him of the correctness of the low dosage of

diphenylsulfone we had prescribed.

"Inexplicable" reactions in two other patients could be traced back to self-applied multiplication (with factors four to ten) of the prescribed doses of diphenylsulfone. (The extra drugs were supplied through relatives in the patient's home country or by other patients "who knew the way"). Long talks were necessary with a foreign laborer who wanted the residuals of his facial lepromatous lesions "burned away." This "active participation" of the patient in the process of cure must be seen as a positive development, even if it is somewhat troublesome to the doctor.

The last phase of treatment begins when a patient has to visit the doctor only every now and then for control. In foreign laborers we did not see any difficulties in this stage. This is possibly so because people have succeeded in making themselves independent again. Relatively fast they learn to live with their "secret." Students remain more dependent on others, and among our patients they had more emotional difficulties than foreign laborers. Only one of them up till now has finished his studies.

To us the best criterium for the successful treatment of a leprosy patient seems to be that the patient plays a self-chosen role in society without any great psychologic difficulties. In general, this will mean that he or she returns to his or her home country. There can be very valid reasons, however, to postpone such a return: visible lesions, expected or real "rejection" at home, good integration in the society of the guest country (marriage!).

Somatic "relapses" are but too well known in the treatment of leprosy. We suspect that they occur even after seemingly good psychologic integration. We thought that one of our patients, who had shown a very rapid somatic improvement of his condition, had coped with his disease excellently. During a small party one of his superiors made a somewhat critical remark to him. He retired from the company, got himself drunk and in this state repeated over and over again: "I'm a leper; I'm a leper."

If reintegration does not succeed, a (financial) dependence on humanitarian and public organizations develops. The problems this creates are usually not medical ones. However, they make the still necessary medical treatment very difficult to carry out. Sooner or later the doctor-patient relation will become disturbed by mistrust.

In the treatment of leprosy the hospital can only assist, precisely because of the psychologic difficulties usually encountered. We should like to plead for ambulatory treatment of leprosy patients in a country like the German Federal Republic, whenever humanly possible. As much attention should be paid to the psychologic and social problems of these patients as to their somatic ones.

SUMMARY

A description is given of some psychologic difficulties which arose during the treatment of 12, mainly foreign, leprosy patients in a hospital in the German Federal Republic.