

The sulfone era, besides its manifold benefits, is responsible for a new, or at least greatly magnified, headache for administrators and social workers of leprosaria—the problem of the reluctant negatives. By this is meant patients who, so far as the status of the disease is concerned, could leave the institution but who do not.

An article by C. B. Lara and J. O. Tiong in this issue reports the findings of a unique inquiry among negatives at the Culion Sanitarium. It was originally an official report to the Director of Hospitals, who in approving the suggestion that it might be published wrote,

I have found [that] the memorandum . . . presents very clearly the many angles of the problem presented by the negatives who are reluctant to leave the sanatoria, thereby creating a burden to the government.

The situation recounted of course has features peculiar to Culion itself—among them the numbers of children born there of parents with leprosy, and the great variety of opportunities for self-support—but there are also features that must be prevalent in many such institutions. The general picture is very different from the idea of the uninformed—and the misinformed—that the patients of leprosaria are all there unwillingly, resentful and ready to leave incontinently once restrictions are abolished. Actually, about 25 per cent of the actual inmates at Culion are negatives

who have stayed on by choice, for one or another of the several reasons brought out by the inquiry.

The 172 "children," several of whom are already married but all of whom were born in the colony and at one time or another showed manifestations of the disease, constitute a special problem. As a group they know nothing of the outside world and would be lost there, helpless in competitive life, especially since they have no place to go because their parents' families are unknown or do not want them. At Culion they are at home and taken care of, and there are various resources for self-help as they grow up. Medically, this group is very interesting because they all once had lesions which disappeared spontaneously (only one girl had taken diasone), and among such cases relapse has been rare.

Many of the 268 adult negatives have been at Culion so long that they have lost connection with the outside world and have no desire to return to it, except perhaps in some instances for an occasional "vacation." Practically two-thirds of them have some degree of deformity, but those who are without deformities don't want to go out, either. They are comfortable and happy at Culion, with none of the struggle for survival of the world outside. Enough is said about the resources of the Culion Reservation that are available to active, ambitious inmates to make it clear how unusual is the place in that respect. The point is rightly made that Culion is more a community than an institution. So it is that many of the negatives, even a majority of those with deformities, could get along—not, however, without hardships in many cases—if the privilege of free rations were withdrawn.

A significant point is how little treatment the Culion patients are taking, many of them because they do not wish to improve to the point of becoming negative and therefore liable to being discharged. This attitude is not, it seems, peculiar to Culion. An official of the Central Luzon Sanitarium has told us, "Many of our patients take enough treatment so the disease does not get worse, but not enough so they get cleared up." That sort of situation, of course, depends upon the cafeteria system of treatment: The patient takes what he wants when he wants it.

The same attitude has been observed even in Korea. Dr. Robert G. Cochrane, in an address given in Seoul early in 1955, after he had spent some weeks visiting leprosy institutions in various parts of the country, said that he felt the patients had little hope of returning to normal life, and that even of those leaving the two places in which he found the best spirit probably few could return to their own homes, the majority resettling themselves in leprosy villages. The general feeling, he said, seemed to be, "Give us sulphone to make us fit, but not enough to make us well!"

It appears that there is, or has been, a more or less similar situation at the U. S. Federal Leprosarium at Carville, La.¹ For many years the number of patients there was in the neighborhood of 400. Late in 1953

¹ Information largely from the *Carville Star*, issues of January and March 1955.

there was a change of policy toward those, who might go home, and the population decreased until it reached the 300 level early in 1955—although, apparently, there were still more than 50 negatives among them.

Under the new policy the patients were classified as of three categories: (1) physically able-bodied, capable of working outside, who were definitely asked to leave; (2) partially disabled, to whom it was suggested that they leave if they could; and (3) the "permanently disabled," such as the blind and severely crippled, who were assured that they would not have to leave although they might do so if they had someone to take care of them. In a protest meeting the patients proposed that a distinction be made between those who had been there for more than a few years and those who had come since sulfone treatment was introduced. This proposal was not adopted, but it is evident that the new policy was not applied ruthlessly. Nevertheless, the patient population was reduced by about one-quarter.

Here are concrete examples of a problem that must exist, with variations, in leprosaria in still other countries and one that is likely to get worse. It is a rehabilitation problem which demands the attention of those who are concerned with the welfare of leprosarium patients who should be ex-patients.

One favorable thing about present-day therapy is that the earlier a patient who has to be hospitalized is found and put under active treatment, with no silly question about whether he wants or does not want to take it, then the quicker his lesions should be cleared up and the less danger would there be of his becoming institutionalized to the point of being incompetent for extramural life. More comforting than that is the thought that patients who get their treatment as outpatients are not separated from their families at all; their problems are different ones. This is an argument in favor of lessening the severity of regulations so as to permit all but the most obviously and seriously infectious cases to be treated as outpatients—a change which, however horrifying to the old-line segregationist, is inevitable where attempts are made to control leprosy by mass treatment in the field.

—H. W. WADE