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## THE PROBLEM OF THE NEGATIVE INMATES IN THE CULION SANITARIUM<sup>1</sup>

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The patients admitted to the Culion Sanitarium have at the time, with rare exceptions, the persistently bacillus-positive forms of leprosy—lepromatous, borderline, or chronic reactional tuberculoid. At any given time, however, some proportion of the inmate population is composed of "negatives," i.e., patients in whom the disease has become arrested and cleared up well enough, and long enough, to permit of their return to the healthy community-at-large as "released" or "discharged" patients without serious risk of their spreading the infection.

In the period between December 1, 1954, and March 31, 1955, when the investigation here reported was made, there were 440 such negatives in the Culion colony. These constitute approximately 25 per cent of the population of the colony who have or have had the disease, or about 20 per cent of the total population including children born of leprosy parents but as yet without signs of infection.

These negatives are considered as of two main categories, one consisting of adults, the other of Culion-born children who have also had the disease but are now free from manifestations. The adult group, numbering 268, comprises patients from different parts of the country who were brought to Culion for segregation and treatment, including a few underage individuals whose closest relatives are legally residents of places outside the Culion reservation. Of the second category, numbering 172, a few are already of age, or if still under legal age they have married in the colony and so may be considered as of age. They are included in the children group because that group comprises those who

<sup>1</sup> This article is an adaptation, with very little modification, of an official report to the director of the Bureau of Hospitals, prepared and published by permission.

had been born in the colony of leprous parents in the last 23 years and have been under special and close observation since birth.

Mainly for the purpose of gaining an insight into their individual problems, each of these negative patients was personally interviewed by one or the other of us, or by both. In the case of the children, their parents or guardians were present at the interview. The information thus gathered, including objective data pertaining to their actual condition of health and social and economic status, have been studied in the hope of reaching some conclusions that might be of help in solving their problems as individuals or groups.

The outstanding problems of both categories of negatives are economic and social. Upwards of 80 per cent of the adult negatives who could go home are not ready or willing to do so. In the case of the children, some of those in the older age levels are willing or even eager to go out, some for curiosity, the others prepared to face any hardships. In most cases, however, there are no relatives ready to take them.

#### THE ADULT NEGATIVES

As of March 31, 1955, there were—as said—268 negatives in the adult group, 139 males and 129 females. Of this number 216, or 81 per cent, are unwilling or unprepared to leave Culion. The principal reasons they gave and the numbers giving them, were as follows:

1. Fear of being shunned because of deformities, 103 patients (48% of the 216);
2. Wife, husband or other relative still here, because still undergoing treatment or for some other reason, 81 patients (37%);
3. Life is easier in Culion than outside, 23 patients (11%); and
4. No relatives waiting for them outside, 9 patients (4%).

*Adult negatives with deformities.*—Of the total of 268 adult negatives 171, or 64 per cent, show deformities in greater or lesser degree, usually of the hands or feet, resulting from the ravages of the disease, while only 97, or 36 per cent, show no such deformities. There is only an insignificant sex difference in this matter, the males with deformities being 65 per cent (91), and the females 62 per cent (80).

If they were to be deprived of government rations, 56 of the 91 adult male negatives with deformities (61%) would be able to support themselves; actually a few of them already are not receiving rations or other privileges except medical treatment. Some are successful store owners, while others are engaged in fishing or other profitable occupations like carpentry, farming, etc. Of the 80 deformed negative adult females, 49 (61%) would also be able to carry on without a ration allowance. In other words, about three-fifths of this group with deformities due to leprosy feel they could still manage to support themselves if deprived of government rations, provided they are allowed to remain in Culion under present conditions.

*Adult negatives without deformities.*—Among the total of 97 adult negatives without deformities there are 48 males, of whom 46 (96%) are physically or economically able to earn a living. Of the 49 females of this group without deformities, 46 (94%) also feel they would be able to earn a living in Culion if deprived of government rations.

Since fully 80 per cent of the adult negatives are not ready or willing to leave Culion, while only about 63 per cent of them show some degree of deformities, an appreciable proportion, approximately 17 per cent, have no deformities but are nevertheless reluctant or unwilling to go out for one of the other reasons stated, namely, that a close relative or spouse is not ready for discharge, or because they find it easier to make a living in Culion than they would outside, or because they no longer have relatives to whom they could or would wish to go.

*Social and economic status of negatives.*—Seventy-four adult male negatives are married here in Culion to other inmates; of these, 60 (81%) can manage to earn their living regardless of government rations. Sixty-five adult male negatives are either married outside or are single or widowed in Culion; of these, only 39 (60%) feel able to get along in Culion if deprived of government rations.

Of the 94 female adult negatives who are married in Culion, 77 (82%) can rely on their own efforts, with or without the help of their husbands, to gain their living in Culion; while of 35 females either married outside or single or widowed in Culion, only 18 (51%) feel they can do so. From this it would seem that the married state while in Culion is an incentive to an inmate to earn a living.

*Treatment among the adult negatives.*—While most of the negatives in the adult group have received some kind of antileprosy treatment, only 60 of them (22%) had actually received any during the last six months; the rest had stopped treatment for one reason or another. As a matter of fact, only approximately 40 per cent of the total of upwards of 1,700 inmates with leprosy are receiving treatment, most of them with sulfone.

The surprisingly low figures for both negatives and other patients taking treatment, considering the generally recognized beneficial effects of modern therapy, are due to various causes. Some patients complain of untoward effects, such as a feeling of weakness or of vertigo—mostly subjective symptoms which are difficult or impossible to verify. Certainly, most such complaints cannot be attributed to the anemia that may result from sulfone therapy, for these patients do not have it. Inquiry reveals the interesting fact that many patients who are not taking treatment, while they wish to improve, do not wish to do so to the extent of becoming negative and eligible for—and in danger of—release or discharge. They prefer staying in Culion to going outside. This is mostly true of patients who have been in Culion for a long time, and so have lost contact with the outside world.

## THE NEGATIVE CHILDREN

In this group there are 172 negatives, practically all of whom were born in Culion. Fifteen of this group are already married with other inmates. Of the remaining 157, 27 are still under 15 years of age and have both parents living in Culion; of the other 130, all of whom have lost one or both of their parents by death, 44 (33%) are still under 15 years. Some are staying with relatives or guardians, and the others are living in dormitories under the care of the missionary groups.<sup>2</sup>

This group of negatives is remarkable from several points of view. Since they were born in Culion, they have never had any contact or close connection with the outside world. While many of them may have more or less distant relatives outside Culion, we have almost never received interested inquiries from such relatives. Only exceptionally, in the years since the liberation in 1945, have we been able to trace any relative willing to accept such children and take them away.

Another outstanding feature about this group is that, with a single exception, that of a girl who had taken diasone, they had never received any kind of antileprosy treatment. In them the disease simply underwent spontaneous resolution and arrest. Further, in cases in which this spontaneous healing has occurred there has very rarely been any tendency to relapse. This observation is the more important for having been based on continuing studies of these children from the time of their birth until the present. This is an observation that has been repeatedly confirmed in the past two decades, and it should be given due consideration in the planning and carrying out of leprosy control work.

Another noteworthy fact is that all of the negative children, without exception, are without any deformity due to the disease. Since practically none of them received any kind of treatment, the absence of lasting marks of the disease indicates exceptional resistance or ability on the part of these young children to overcome the infection even after manifestations of the disease have appeared.

Of the 15 negative "children" who are already married, 13 are females and 2 are males. Of this small group, only one female could not manage to earn a living if deprived of rations; she has several children and her husband, a positive case with some handicap, has a very low earning capacity.

Of 27 underage children with both parents still living, only 1 out of 11 males and 6 out of 16 females would not be able to earn a living if deprived of government support. The reasons that these 7 could not get along are either that they are too young, or that their parents are handicapped physically or economically.

Of 69 underage children with only guardians or one parent living in Culion, 27 (39%) are handicapped economically or still too young to earn

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<sup>2</sup> The data on ages apply to the time the interviews were made.

their living, while of 61 female children of the same category, 26 (43%) would be in similar plight if deprived of government support.

#### DISCUSSION

Before we offer definite suggestions for the solving or easing up of some of the problems of the negative inmates, it may be well to consider some of the basic conditions which indicate or qualify the need for the specific remedial measures to be recommended.

It should first of all be pointed out that the Culion Sanitarium, which is a government-maintained institution, with all the available natural resources of the whole Culion Reservation,<sup>3</sup> underlies the psychologic as well as the actual economic status of its inmates. An annual appropriation of over four-fifths of a million pesos<sup>4</sup> for the general and medical care of the inmates and the maintenance of the institution provides both the direct support and the economic basis for all of the individuals as well as the community of inmates as a whole.

The productive efforts of the patients are stimulated by available government-paid jobs or work projects for more than 10 per cent of the inmates. There is also the need to provide such subsistence and other supplies as can be produced locally, such as vegetables and other agricultural products,<sup>5</sup> fresh fish and meat for the patients, and forest materials needed for repair and construction. The bulk of all these various products (i.e., what the producers themselves do not use) is purchased by the government, for redistribution to the inmates generally as free rations and other supplies. Approximately 25 per cent of the whole appropriation for the sanitarium is expended directly for these services and materials. These material incentives serve to maintain the desire of the more active and ambitious among the inmates to prolong their stay in Culion.

Furthermore, in other respects the Culion Sanitarium is like any other medium-sized provincial community. Here, intermarriage and the attendant raising of families occur among the inmates as naturally as in other communities; and, in addition, all the various activities that may be found as part of the life of an average community are also found in Culion.

Not the least of the special features or advantages to the inmates of this colony, in its role as a community rather than a sanitarium, is the great psychologic factor that they feel entirely free from the shame or humiliation which leprosy, by tradition, imposes as a social stigma on individual patients and their families when living in the ordinary "non-leprous" community.

<sup>3</sup> The land area of Culion and the several other islands within the reservation totals approximately between 150 and 200 square miles. The entire area is about 260 square miles.

<sup>4</sup> The Philippine peso is the equivalent of US\$0.50.

<sup>5</sup> The products include some rice, grown by the upland *kaingin* method, although the regular rice issue is imported from Manila.

Considering all these advantages now enjoyed by the inmates, it is not surprising that the majority of the negatives—and we believe this is likewise true of the positive inmates—prefer to remain here, provided government support is continued and conditions continue to favor their present economic situation.

The reluctance, therefore, of many adult negatives to be released or discharged, or of parents and guardians who have still to remain in Culion to send out their negative children, is based in large part on the belief that life in this institution is easier and more bearable than it would be outside. It should be realized, however, that these advantages are to a large extent only temporary and apparent, and subject to changes of government policy. It is possible, for example, for a considerable proportion of the appropriation which, as explained, goes to provide for jobs for more than 10 per cent of the population, to be greatly reduced or shifted. That would naturally affect the general economy of the place.

In the case of the negative children, for example, about one-third of those who, under existing conditions, could be deprived of government rations and other privileges, if allowed to remain in Culion at all, are either children or wards of patients who are actually employed as inmate assistants. Similarly, practically one-half of the adult negatives who could now be deprived of government rations and other privileges either are actually employed themselves or have spouses or other close relatives who are employed and so are able to support them. Thus, among all the negatives, adults as well as children, who feel they could if necessary forego their government rations and other privileges, provided they are allowed to stay in Culion, only 60 per cent would really be able to support themselves if negatives now in actual employment should be deprived of their positions in favor of bacteriologically positive inmates.

Notwithstanding all that has been said in favor of Culion and about the attitude of many of the inmates, it should nevertheless be remembered there are some of them who are really anxious to return to their homes. With the present effective methods of treatment and the liberalized policy regarding segregation and treatment, the outlook is now vastly happier for this small group of patients. The problems should not be difficult for those who have means to permit them to reestablish themselves again in their home towns. Unfortunately, however, the majority of the inmates come from the lower economic strata. For them it would be difficult indeed, being socially stigmatized and perhaps physically handicapped, to achieve rehabilitation to normal community life. Quite a few, also, of the Culion inmates have lost their contact with relatives at home for other reasons, such as illiteracy and inability to communicate with them, broken family ties and loyalties, and trouble arising from unjust disposition of family properties.

RECOMMENDATIONS<sup>6</sup>

The following recommendations are offered as a means of providing immediate as well as eventual relief for only some of the more obvious problems of our inmates, whether still positive or already negative.

1. There is great need for an experienced social worker, endowed with a great fund of human sympathy, to maintain frequent contact with inmates who are in need not only of material or moral support but also of keeping in close touch with relatives at home.

2. Those agents and officials authorized by law to help secure and protect properties of inmates confined in the sanitarium<sup>7</sup> should apply all the authority and influence of their positions toward this end, whenever such an inmate is in need of help.

3. There is also great need for effective means of improving the productivity of the inmates, especially in regard to farm crops and livestock, which could be disposed of in the general open market or at least redistributed under government supervision to other sanitariums where it is not possible to produce such supplies.

4. As much as possible the government and the educational agencies in the sanitarium, especially Culion, should make it part of their major activity to encourage and train able-bodied inmates toward self-reliance and productive work. As soon as possible there should be withdrawal of government privileges, but that should go hand in hand with improved ability on the part of the inmate to produce. Attainment of self-reliance should be given appropriate recognition as a meritorious accomplishment. In other words, the tendency to pamper the inmates and to provide for all their needs without cost or effort on their part should be revised.

5. A further incentive to self-reliance would be to make provisions so that deserving inmates would be allowed permanent title of ownership to land and other real properties which they develop within the sanitarium, provided that such properties be not sold, transferred or otherwise disposed of to persons who are not patients or members of immediate families of patients.

## CONCLUDING COMMENT

In the foregoing discussion, the problems of the negatives in Culion have been considered chiefly from the viewpoint of the negatives themselves. Of scarcely less importance, however, are the economic and public health aspects from the viewpoint of the government, which may result from the long-continued stay of negatives in Culion and the other sanitariums.

<sup>6</sup> These recommendations, a part of the original memorandum not designed for publication, are regarded as of sufficient general interest to be retained in this version of the report.—EDITOR.

<sup>7</sup> The term "sanitarium" as used here refers to the leprosy institutions of the country in general.

Many of the negatives are still within, or eventually will pass through, the active reproductive period of life. With unrestricted intermarriage among the inmates, and absence of birth control as a policy, the prolonged presence of many negatives in the sanatoria will eventually result in increased numbers of births. Since young children are notoriously susceptible to leprosy infection, especially under conditions of unlimited exposure such as those prevailing in sanatoria, many of the offspring of such negatives will ultimately become infected and develop the disease, thus perpetuating the process of transmission of the disease from one generation to another.

It should, however, be stated as a possibility that even if all negative inmates were to be obliged to return to the world outside, many of them may still be expected eventually to beget offspring. It is not at all certain, in the present state of knowledge, that the children of such negatives will always be free from the risk of developing leprosy, even when not exposed to a massively infected environment.

The exact method or methods of the transmission and of the pathogenesis of leprosy are by no means completely elucidated. For this reason, and pending adoption of a new policy that offers some relief from the viewpoint not only of the negatives themselves but also of the government, and more particularly the public health, more intensive scientific studies of the questions of natural transmission and prevention are greatly to be desired.

#### SUMMARY

This article, adopted from an official memorandum not designed for publication, deals with the problems of the "negatives" at the Culion Sanitarium, i.e., those inmates whose disease has so thoroughly cleared up that they are entitled to release or discharge. There are 440 such individuals, constituting about 25 per cent of the inmate population. They are of two categories, namely, adults (268) brought from elsewhere as patients, and children (172) born at Culion who have shown manifestations of the disease but are now clean.

Among the adults, 216 (81%) are unwilling or unprepared to leave. The reasons most frequently given are difficulties arising from mutilations due to the disease (171 adults have them in some degree), or the desire not to leave spouses or other relatives not ready for discharge. An important factor, discussed from more than one point of view, is the normality of life in the Culion Reservation and the many opportunities of self-help.

Incidentally, less than one-quarter of the adult negatives had taken any treatment during the past six months. Even among the patients still bacteriologically positive, less than one-half are taking treatment, in some cases because of difficulties with sulfone, but more often because they do not wish to become negative and therefore liable to be discharged. Many,



but by no means all, have been at Culi6n so long that they have lost contact with the outside world.

The negative-children group, almost all without interested relatives outside and 15 of them are already married to other inmates, is an especially interesting one from several points of view. They have had no outside contacts and therefore are highly "institution-minded." With a single exception, they have had no antileprosy treatment; their lesions disappeared spontaneously, not one of them showing any deformity resulting from the disease. Such cases have rarely shown any tendency to relapse.

The conditions of life of patients at Culi6n are discussed. Recommendations are offered which, although intended only for local application, have features of wider interest.

#### RESUMEN

Este trabajo, adaptado de un memor6ndum oficial que no estaba destinado a publicaci6n, trata de los problemas de los "negativos" del Sanitario de Culi6n, es decir, de los asilados cuya enfermedad se ha desvanecido tan perfectamente que tienen derecho al alta condicional o absoluta. Hay 440 de esos individuos, formando 25 por ciento de los residentes. Corresponden a dos clases, a saber, adultos (268) traídos de otras partes en calidad de enfermos, y ni6os (172) nacidos en Culi6n que han revelado manifestaciones de la dolencia, pero que hoy día se hallan desembarazados de ella.

Entre los adultos, 216 (81 por ciento) no est6n dispuestos o preparados para abandonar el establecimiento. Las razones alegadas m6s frecuentemente son las dificultades derivadas de las mutilaciones debidas a la enfermedad (171 adultos las tienen en mayor o menor grado), o el deseo de no abandonar c6nyuges u otros parientes que no est6n capacitados para el alta. Un factor importante, discutido desde m6s de un punto de vista, es la normalidad de la vida llevada en el recinto de Culi6n y las muchas oportunidades ofrecidas allí para ayudarse a sί propios.

Incidentalmente, menos de la cuarta parte de los negativos adultos habían recibido alg6n tratamiento durante los 6ltimos seis meses. Aun entre los enfermos todavía positivos bacteriol6gicamente, menos de la mitad tomaban tratamiento, en algunos casos debido a dificultades con la sulfona, pero m6s a menudo por no desear volverse negativos y verse expuestos a ser dados de alta. Muchos, pero no todos en modo alguno, han permanecido en Culi6n tanto tiempo que han perdido contacto con el exterior.

El grupo de ni6os negativos, casi todos sin parientes interesados fuera de la colonia y 15 de ellos ya casados con otros asilados, resulta en particular interesante desde varios puntos de vista. No han tenido contactos con el mundo exterior, y por ello, tienen la mente fija en el establecimiento. Con una sola excepci6n, no han recibido tratamiento antileproso; sus lesiones han desaparecido espont6neamente, sin que ninguno muestre la menor deformidad procedente de la dolencia. Esos casos rara vez han mostrado la menor tendencia a recidivas.

Disc6tense las condiciones de la vida de los enfermos en Culi6n. Ofrecense recomendaciones que, aunque destinadas solamente a aplicaci6n local, poseen características de alcance m6s amplio.

#### ACKNOWLEDGMENT

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