THE VALUE OF LEPROSY VILLAGES IN A PROGRAM OF PREVENTION

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Isolation is the first thing to be used for the control of many contagious diseases, until more effective means are developed. With leprosy, science having been baffled in that the causative organism has not been cultivated satisfactorily and the disease cannot be produced at will in experimental animals, some form of isolation is relied upon as the chief tool of prevention. On the other hand, because of the usual long period between infection and the development of the disease, and the years that the patient may have it without becoming completely disabled, isolation becomes quite a different procedure from that which can be used with scarlet fever or smallpox. The cost of isolating a patient for from five to twenty years, the resentment that he develops during the long period of separation, and the psychologic build-up within him, all unite to prevent universal isolation of even those leprosy patients which are regarded as most infectious, those with the lepromatous form of the disease.

One of the questions today is what is the minimum amount of isolation needed for leprosy control, as well as the type of isolation which best serves the purpose. There are types of leprosy which do not call for isolation, although the patients should be checked periodically lest they become contagious. Complete isolation is never indicated. There is no evidence that leprosy patients begging on the street cause the spread of the disease. It is what they do when they are not begging that is of importance. From such information as we have, it seems to be more important to prevent young persons up to 20 years of age from coming into contact with the leprosy patient than it is to keep the latter from all contacts with other adults.

CAUSES OF THE SPREAD OF LEPROSY

The most important factor in the spread of leprosy is home contact. This is said although there are many homes in which leprosy patients live without other members of those households developing the disease. There are problems in that connection, but this is the custom of all contagious diseases: always there are some persons, who, because of immunity, or lack of a massive infection, or some other unknown factors, do not succumb. This is very evident in leprosy and tuberculosis.

Experience has shown that children are the most susceptible of all age groups. Certain leprologists have held that all leprosy cases are infected during the early years of childhood, but there are many cases

in which that is not true. Nevertheless, it is a fact that childhood is the most dangerous period, and special care should be taken to avoid contact then.

The next important factor is familial susceptibility. Aycock has shown this in his epidemiological studies, and all who have worked with leprosy realize its importance.

Finally there is a factor which is much harder to demonstrate, that of lowered general resistance on the part of the individual, and the things that cause it. First there must be present the leprosy infection, but a latent infection may be activated and brought out by a subsequent awakening condition such as chronic malaria, chronic appendicitis, or the like.

In determining the form of isolation to be used account should, so far as possible, be taken of these known factors which favor its spread.

FORMS OF ISOLATION

Only passing mention is made of the most drastic of all methods, that of killing the patient and burning his remains and his house. This has been done, even in recent years.

Not much better from certain points of view is a method employed in some places which involves a longer period of torture—the prison colony. By a "prison colony" is meant an area set aside for the isolation of all leprosy patients sent to it. There is usually a wall or a well-made fence around it;[1] sometimes there is no wall, but patients are not allowed to leave without permission. Anything which restricts the coming and going of a person inevitably produces the prison psychology, no matter if the prison offers hotel services. Experience has shown that such colonies surely cause early cases to hide their condition as long as possible.

There is also the colony in which normal freedom is allowed but which is so far from civilization or social contacts that neither patients nor personnel can be easily persuaded to go there. If large colonies are desired for any reason they should be located in favorable areas, and the rules must be made for the benefit of the patients in such a way that the rest of the world receives adequate protection.

Another major form of isolation is the leprosy village, where citizens live as do those of normal communities. They have farms and gardens, they do trading, and they come and go as any normal person. The government of the village is the same as that of any village, except that there are no taxes, and medicine is provided. Usually these villages are quite close to other villages. The important feature is that the leprosy patient does not visit the homes of people outside of his village, and he is not persecuted by the people of his own village. The psychology is excellent, and the isolation is satisfactory.

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[1] This does not refer to fences usually needed for protection against outside marauders.

At times, because of the low incidence of leprosy or for other reasons, there are patients who cannot go to a village. A separate house may be built for him in his own village, good isolation being thus provided. Finally, there is the possibility of room isolation. A certain room in a house is kept for the leprosy patient, with a separate outside entrance and separate lavatory facilities. Although these last two methods of isolation are feasible in certain cases in a public health program, they are of minimal importance.

VILLAGE ISOLATION

It is the purpose of this paper to draw attention to the value of village isolation. Actual experience of more than twenty years in parts of Thailand and Burma provides material which leads to certain conclusions.

By village isolation we mean the formation of small villages by and for persons with leprosy, which places may increase in size as their numbers demand. Experience has shown that unless a community has at least 20 cases it will not continue to exist. This number is the minimum for safety, and for the provision of the many different things needed to maintain a village such as the building of houses, raising of animals, and planting of garden products in variety.

The village usually starts in a sort of normal way, although it is possible actually to choose a site and plan for several families to go and build on it. In the latter case much more expense is involved because outside help is necessary to build up quickly. In the normal way, after two or four families have built other people with leprosy join them. The reason for this is psychological. Misery loves comfort, and the cursing and persecution which these people ordinarily experience is absent where all suffer alike. Here lies one of the weaknesses of a leprosy village: many of the people are deformed. If they were not deformed, they would not have been persecuted. Therefore, many of the patients with the disease in the earlier stages resent being asked to join up with these horrible advanced ones. They resist until they, too, have become crippled and are cursed. However, persons with early leprosy who are related to people of the village may come to live there.

As time goes on, if it is desirable to make this village more stable and to prevent as far as possible begging in the nearby community, certain aid may be given. Rice fields may be purchased for the villages to cultivate. If the cripples are unable to work the fields themselves, the profit from renting the fields to others will keep them supplied with rice for their own needs. Buffalo to work the fields or to rent out are also a great help. In providing such helps it is wise not to allow the actual ownership to reside with the patients, but with some outside person or group interested in the work. This prevents abuse or selling of the property. When giving such help it should be understood that one-tenth to one-fifth of the produce should be given to help other cripples. Pigs may be

purchased from a revolving pig fund; the hog when sold provides sufficient money to defray the initial cost and to buy more pigs. Usually there is a little profit, so that the fund steadily increases. Bullocks with carts may be purchased for the more energetic villagers, to be paid for out of the profits of hire, the cart eventually belonging to the patient.

The leaders of the village are usually elected by their fellows, although sometimes they are appointed by those helping the work from the central colony. The medical assistant, the one person who handles all the drugs used, is preferably a patient—usually a noninfectious one—trained for this work in the central colony. He may be paid partly by the villagers giving him a little paddy each year, or other useful material, and partly he may be helped from the central colony.

There are important advantages in this type of village isolation. Perhaps the most important advantage is that the people are happy. They are not removed from their normal surroundings; they live as they are accustomed to do; there is freedom. There is a place to which they can come and not be abused or persecuted.

This kind of relative isolation is satisfactory isolation. It has been impossible, to date, to locate a single case of leprosy which has developed because of contact with one of these village cases by a person who lived outside the village. There probably are such cases, but they certainly are rare. Although a much more thorough program is needed to reach all the leprosy cases of an area, the village is an excellent beginning when funds and public opinion are not ready for a more intensive type of work. Furthermore, if a more extensive control village unit program is begun these villages offer an excellent point of departure for the better type of work. They are the most economical form of leprosy segregation. Actually, even if outside help is lacking for long periods of time, the isolation still continues. The cost is less than one-tenth that of large colonies in which people are given full support. The rate of recovery in these village colonies is apparently as good as in central colonies, if not better. Large numbers of these villages can be supervised by a very small force of trained medical workers. There is no limit to the number of such villages that can be developed if the prevalence of leprosy demands it. Laws requiring people to live in, or to visit villages at clinic times, can be made without jeopardizing the whole antileprosy program.

There are disadvantages, some apparent but not real, some that are real. One of the first objections comes from the nearby normal villages. Nobody wants people with leprosy living near him. The fact remains, however, that something must be done about leprosy, and the isolation place is bound to be near some ordinary village. Like a broken arm, the problem cannot be ignored but must be treated where the trouble is. The transporting of leprosy patients to places far distant from where they originate cannot be done everywhere. It is impossible financially, and it is usually impossible to persuade the patients to accept the change.

It is often said, and correctly, that once a leprosy concentration is established, persons with the disease tend to come to it from distant places. Often they do not actually live in the isolation village, but merely increase the total leprosy population of the area. Although this is true, it is no reason to stop our efforts to get at the root of the trouble—the eventual lowering of the prevalence of leprosy and finally its elimination. This problem must be dealt with at the point where it exists.

Begging by the inmates of the village is a nuisance. This occurs when they are not properly looked after. It should be remembered, however, that it is only a nuisance, and there is no proof that it is a cause of spreading leprosy. When proper efforts are made to look after the beggars, they will cease to beg.

Another objection, one of real importance, is the fact that often the husband or wife does not have leprosy, and that the children of the patients are under continual exposure. A partial answer to this is that they would be equally exposed if they lived elsewhere, for it is impossible to develop an extensive program which would prevent this entirely. It may possibly be that with the use of preventive doses of the sulfone drugs these people may be made secure.

It is also said that village isolation is not the proper way to develop a preventive program against leprosy. It may not be the ideal way, but it is probably the best practical way to make a solid beginning. Because we cannot have the best is no reason for doing nothing.

ACTUAL EXPERIENCE WITH LEPROSY VILLAGES

1. The village of Whey E Ling, some sixty km. from the large central colony at Chiengmai, was established 40 years ago by a local official who set aside a large tract of land—2 km. long and 1 km. wide—and ordered all persons with leprosy in his area—some 30 km. in diameter—to go there to live. About 50 such people did so. Their children were not allowed to go. Some individuals who did not belong in that particular area found their way there, but in general it consisted of the majority of leprosy patients in the Jaum Taong *umphur*, or district. Forty years later what is the picture? One of the original inmates still lives there with his wife; all the others have died. During the war as the inmates died the children, who had not been allowed to live there or had come in slowly later on, claimed the land as their own. All that land has been reclaimed by well people, and only the section on which the original patient lives is now available for leprosy patients.

The work has been revived, and there are now some 50 patients at the place or near enough to it so that they come there for treatment. None of these patients is a contact of any of the original group. There is no evidence of any spread because of the people who had lived in village isolation. There was and is free contact with the adjoining villages. All

the patients now here developed leprosy in distant villages and have come here for treatment, comfort and security.

2. The leprosy village of Jaum Tong. A small village of over 80 patients adjacent to the large *umphur* village of the same name, 57 km. from the central colony in Chiengmai. This leprosy village was started about 20 years ago. Medical supervision here, as in Whey E Ling, has been provided from Chiengmai. It is commonly said that it began as a split of the first village, but that is not so according to the inmates who remember the place from its beginning. It started first around a Bhuddist priest who had leprosy and lived in his temple until he died. Around him gathered many other persons with the disease. For purely personal reasons 4 or 5 from the first village came to Jaum Tong, just as some from Jaum Tong have gone to Whey E Ling. Careful questioning of all the patients here did not reveal a single instance of the infection having been contracted from people of the leprosy village. Many of the patients have come from far distant places, and some are children of leprous persons of this village.

The actual number of cases does not diminish. Twenty years ago there were 80 cases, and today there is about the same number although the actual persons are different. It has been reported by the local officials of the town of Jaum Tong that leprosy is on the increase there, but the facts do not support this assertion. Improvements in the method of treating and caring for these people has encouraged more to come here from distant places, but there is no statistical evidence to show that in this particular town there has been an increase in the numbers of leprosy cases.

3. Pa Ka Chereung, a village 42 km. from Chiengmai, situated like the other two in the *umphur* of Jaum Taong. This village started in 1948, six years ago, with one person with leprosy from a far-off village who, with his brother, came to live here because of persecution and unhappiness at home. Little by little others have come from all directions. Although the place was uninhabited when these leprosy people began coming, since that time many well people have settled nearby, and they often try to force the evacuation of the others. However, because leprosy patients must have somewhere to live, they have been encouraged to stay and let the late-comers move away. This situation is related to show that the common people are not particular afraid of leprosy, they simply do not like to see the cripples about. This village colony has steadily increased until there are about 40 registered. As yet there is no evidence of any spreading of the disease. The experience of the two older colonies is that there will be no such evidence, except in the cases of children whose parents are infected.

INFLUENCE OF LEPROSY VILLAGES ON ADJACENT COMMUNITIES

There are several ways of attempting to determine the influence of these villages on the healthy communities near them. One way is to ask the local officials if the disease is on the increase or decrease. They will

give opinions, but usually there are no facts on which they are based. For this reason, and because these officials are subject to rotation, their opinions are not valid. The question may be asked of old inhabitants, or persons who themselves have leprosy and have lived in the area for years, and if these people are keen observers their information may be helpful.

The only certain way of determining the influence of the villages on the occurrence of leprosy is to have records covering many years of experience, and these are what we have attempted to obtain. The facts as revealed by these records were surprising. They show that there is no evidence of a true increase in the prevalence of leprosy. Because of increased efforts in prevention and treatment new cases have been discovered, but these cases are in no way related to the leprosy villages. They are usually living peacefully and harmfully at home, the probable source of the continued increase of cases over the years.

Active workers in the leprosy village eventually succeed in persuading these "silent" cases to take medicine, and thus the village is really a benefit. It is also true that persons with leprosy living at some distance from the colony hear of the help they may receive, and for one reason or another move to that area. This gives a false picture of the prevalence in that particular area. If a true picture is desired it will be necessary to take a census of villages at considerable distances from the leprosy villages.

The people living near these colonies soon become accustomed to persons with leprosy being around, and do not really fear them. Of course, if they are questioned they will say they wish that the patients might be made to move to some place further off. Certain obnoxious beggars are a real nuisance. However, so far as well people doing anything bad for the afflicted ones—or anything good, for that matter—it rarely happens.

CONCLUSIONS

It may be asked why, if leprosy villages are of real value in lowering the prevalence of the disease, they still have as many cases as they had 20 or 30 years ago. The answer is that the new cases which keep the village-colony population constant come from areas where nothing is being done for them or the disease. The untouched or inadequately provided-for areas are the main source of the new cases.

It is granted that, if funds were adequate, a much more detailed control program should be carried out. With the lack of funds for leprosy work that exists in Thailand the leprosy village is the most logical and economical method of meeting the problem. Without trained personnel the leprosy village can be administered by patients, and a large number of these villages can be supervised by a very small group of medical men.

These villages offer an excellent opportunity for the study of various problems connected with leprosy. New treatments can be checked to prove their value in field preventive work. Preventive procedures of a more

intensive nature, such as village control units and special clinics as used in India, can make these villages as their starting points.

While comprehensive plans are being developed, needed budgets provided, and personnel trained, the leprosy village is providing a satisfactory means of isolation, holding the problem at least at a standstill.

SUMARIO

En el estado actual de nuestros conocimientos acerca de la lepra, el aislamiento en alguna forma constituye uno de nuestros importantes instrumentos de prevención. El establecimiento de colonias (leproserías) como uno de los principales medios de aislamiento resulta a menudo económicamente imposible para las zonas de alta incidencia, y es sociológicamente inaceptable para e enfermo. Las aldeas para leprosos, debidamente regidas, son relativamente poco costosas y son aceptables para los enfermos. Las desventajas de estas aldeas son: tal vez queden demasiado cerca de aldeas de personas sanas; suelen atraer enfermos de sitios lejanos; suele haber alguna medicidad de parte de algunos de los enfermos; y parientes sanos conviven con los enfermos. Todas estas desventajas son un hecho, pero otro tanto reza por igual con los enfermos que viven sin estar aislados.

El análisis exacto de lo observado en tres de esas aldeas, cuya existencia se remonta a cuarenta, veinte y seis años, respectivemente, no revela ninguna infección por contact, excepto en casos de hijos de los enfermos. Al terminar, cabe preguntar por qué no ha sido rebajada la incidencia de la lepra por este plan de aldeas. La razón es sencilla: el plan no ha sido empleado universalmente ni apoyado adecuadamente.