

Leprosy Control in the Teso District, Uganda—A Review of the Last Twenty Years*

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Teso District is in Eastern Uganda with an area of 4500 sq. miles (11,500 sq. km.) and a population, based on the 1959 census, of 500,000. All belong to the same ethnic group and speak a language different from that of the Bantu people to the south and of the Nilotic group to the north. In a series of surveys prior to 1955 the leprosy prevalence rate was found to be 25 per 1000, meaning that the number of patients in Teso at that time was around 12,000; 20% were under the age of 15.

The Kumi Leprosy Centre consists of 2 units, one for children under the age of 16 at Kumi, and one for adults at Ongino 5 miles away, both under the same supervision. The beginnings go back to 1927, when 5 out-patient clinics were organized for the injection of leprosy patients with hydnocarpus oil. In 1930 concentration of this treatment was on a settlement at Kumi for children, because of the serious nature of the disease (not unlike that with which I became familiar on my arrival in 1949) and because, with a very scattered population, treatment could not be made available to many children who, to obtain it, would have had to walk many miles each week in all kinds of weather. The Ongino settlement for adults followed later, but

it had to be built some distance away because it was not easy to obtain the land to add the adult unit to the children's settlement.

About 1950-51 a major change to more effective treatment became possible when gradually the sulphone drugs were introduced. The addition of sulphonamides, antibiotics and other drugs specific for the many complications which were more serious for patients suffering from leprosy, completely changed the outlook; but with the advent of these new weapons the effort of settlements was confined almost exclusively to the patients for whom there was bed-space or for those who did not live too far away to attend as out-patients. The fact remained, however, that in the whole of Uganda, with a population of 6 million dispersed over an area of 93,000 sq. miles (238,000 sq. km.) there, were between 80,000 and 90,000 patients, only 5% of whom had access to any treatment.

The problem in Teso was a reflection of that in Uganda. The people live in scattered family units, not in villages or towns as in other countries. The average population density was 60 per sq. mile (about 22 per sq. km.), but this was an average, and in some areas the people were even more dispersed; also there were no communal centres where people could gather. It was estimated that if Uganda had 1000 clinics organized uniformly, 75% of the patients would still have to make a return journey of 8 to 12 miles to obtain treatment. This was a physical impossibility for children and for those with complications, and in any case attendance depended upon the weather, for some roads and footpaths in the wet season might be impassable for weeks.

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In Teso, to provide even this kind of skeleton service 60 clinics of one kind or another would have been needed. It was decided to make a beginning by putting a treatment village in each county (except Kumi which already had the Leprosy Centre). These villages were built and occupied by the end of 1955. At first, between 90 and 100 patients lived in each village, and large numbers of out-patients attended the village clinics. The villages were built by communal effort and patients who had far to travel could live in them and farm there. The primary object was not segregation for its own sake, but to create a hopeful community that could get treatment easily. The rapid response by the chiefs, the Health staff and the people in Teso created the dilemma of how to handle so many patients efficiently. A system of training paramedical personnel, approved and maintained by the District Councils that would ultimately guarantee them employment, was the next step and was essential to deal with the number of patients who applied for treatment. These numbers were in line with the official predictions from the surveys.

A village system was originally developed in Southern Nigeria in the early 1930's. Segregation of the patients was necessary to control the disease at that time, but it was even more necessary then to deal with the serious social consequences when the patients and the uninfected lived together. There the healthy people had not only an intense fear of contracting the disease if they assisted patients with leprosy, but because they believed that death was the end and that only death would enable the patient to be born again into a new healthy life in the tribe, they went so far as to drive patients from their homes, and often thought they were doing right if, by withholding food or using more drastic methods, an early death was precipitated. The patients lived in dread of the curse they thought had been inflicted on them as a punishment and lived in a state of terror. Some even left home to form new villages. There, a life of segregation was chosen by the patients themselves and was

merciful, besides being the means of preventing the spread of the disease.

In Uganda the situation was happily different, but the difficulty was to get the medicine to the people who, by virtue of their natural dispersal, were to a large extent segregated. The settlements catering for a minority may have given the impression that an attempt was being made to control the disease, but in actual fact this was not so, because treatment of the few is not control of the many. Dr. Kinnear Brown was appointed as Consultant to the Uganda Government in 1951 and, after making a large number of surveys, he suggested a village-clinic system to overcome the problems created by the social pattern. This was accepted with enthusiasm in Teso and had begun to function by the end of 1955.

Treatment and control are not the same thing unless they are closely linked in the combined effort. The village-clinic system and the following up of contacts together provide what is necessary. The skeleton service mentioned as the ideal, which would still put a strain on patients wanting to attend, was not economically feasible because of the lack of housing, money and personnel. The choice finally made was within the resources available and took into account the social pattern. If patients are not to have to travel long distances, then the leprosy assistant must do so instead. What exists in Teso is a compromise between the ideal and the practicable. At the end of 1966 there were 8 leprosy assistants based in 7 villages and responsible for 16 other clinics. This has worked well and its success has depended upon the loyalty of those in the service and the closeness of the supervision. In 1967 one treatment village was closed for lack of patients. Concentration in that county can now be on out-patients. The number of patients living in each of the remaining villages has fallen to between 35 and 40. It is now the plan to cut maintenance costs and to make the treatment villages more attractive by building a nucleus of permanent houses for about 16 patients on each of the village sites and by adding a better dispensary,

and also a permanent house for the leprosy assistant in charge. While it is hoped that leprosy will not always be with us, long-term provision must nevertheless be made for a smaller number of patients.

The number of out-patients attending the various clinics averages 50 or less. As the number of in-patients has decreased, 9 other treatment clinics have been opened since 1967, but they have not brought in many new patients, i.e., patients who have not previously had treatment elsewhere. When new centres are opened it is very necessary to scrutinize past records to make sure that "new" cases really are new. The number now believed cured and no longer needing treatment is very encouraging. Between 1952 and 1961, 7950 patients were treated and 3500 officially discharged. It appeared at one time, after the first influx, that the number of new patients presenting each year was beginning to level out. In 1958, when some degree of stability had been reached, the number of new patients, that is, those attending for the first time, was in the region of 1000, but last year (1968) it had declined to 400, a satisfactory fall in 10 years of 60%. The patients now under treatment include those with chronic lepromatous or unstable disease and those needing individual attention for the complications which can develop early. The remainder are the new and early cases; some of these may resolve spontaneously and are carefully watched, but others obviously need treatment from the beginning.

The number of new patients with lepromatous leprosy coming forward for treatment has shown a marked decline, particularly in the last 5 years. It is significant that a number of those we see are from a group of patients who discontinued treatment: two I know to be patients who were not lepromatous originally, who were discharged, and whose lesions have become active again.

Many schemes are successful at the beginning, but when prolonged after the first impetus has gone and the early enthusiasm has waned they may reach a critical stage when no signs of

progress can be detected. This was so at one stage in Teso, but in 1960 the trial of BCG vaccination against leprosy was introduced, with the support of the Uganda Government, the Ministry of Overseas Development, and the British Medical Research Council. This trial gave a new impetus which, I think, has led to a reduction in the number of new patients. The trial itself is concerned only with 19,000 children, some 9000 of whom were vaccinated, and it is its secondary effect which leads to the main point of this paper. During the routine follow-up examinations of the children in the trial a further 32,000 children have been vaccinated, but they are not included in the trial. The number of children in Teso under 15 is in the region of 165,000. Many of the vaccinated children are barely of an age to contract leprosy. The essential factor is *that a leprosy-minded team has been going into every parish in the district regularly for the past 10 years*, and apart from the trial, children and adults who have had leprosy and others with suspicious lesions are produced or have come forward for assessment and diagnosis. This has meant vigorous control and has led to a dramatic fall in the incidence of leprosy.

This report is not an attempt to advocate a trial of BCG in every district, but rather to emphasize the kind of effort required everywhere. The BCG trial, a separate issue, has simplified the work in Teso, has increased the leprosy effort and not detracted from it, and has demonstrated how important it is to concentrate adequately on the field, for this will then increase the usefulness of the provisions made at settlements. The BCG trial itself has been described separately (Brown *et al.*, 1966, 1968 and 1969) and in Uganda BCG vaccination has given 80% protection against the type of leprosy occurring now in children.

Settlements are needed to deal with those requiring individual attention, and it is important that their attitude should be scientific as well as humanitarian. They alone cannot cope with a countrywide programme nor can a

country do without them. The answer to leprosy, a rural and not an urban disease, lies where it is found, that is, *in the field*. I have mentioned the type of leprosy in children when the Kumi Settlement was first begun and the serious nature of the cases when I first came to Uganda. Besides the reduction in the number of adult patients, I see today a much milder form in the children.

At the end of 1967, of the 200 Teso children resident at Kumi 100 had single lesions. The vast majority had established and extending lesions which justified treatment. There were only 6 children with lepromatous leprosy from Teso. This encourages the hope that by treating early cases as they arise, it will be possible to reduce the incidence of leprosy to the insignificant level of that of tuberculosis now prevailing in countries where that disease was once a serious problem.

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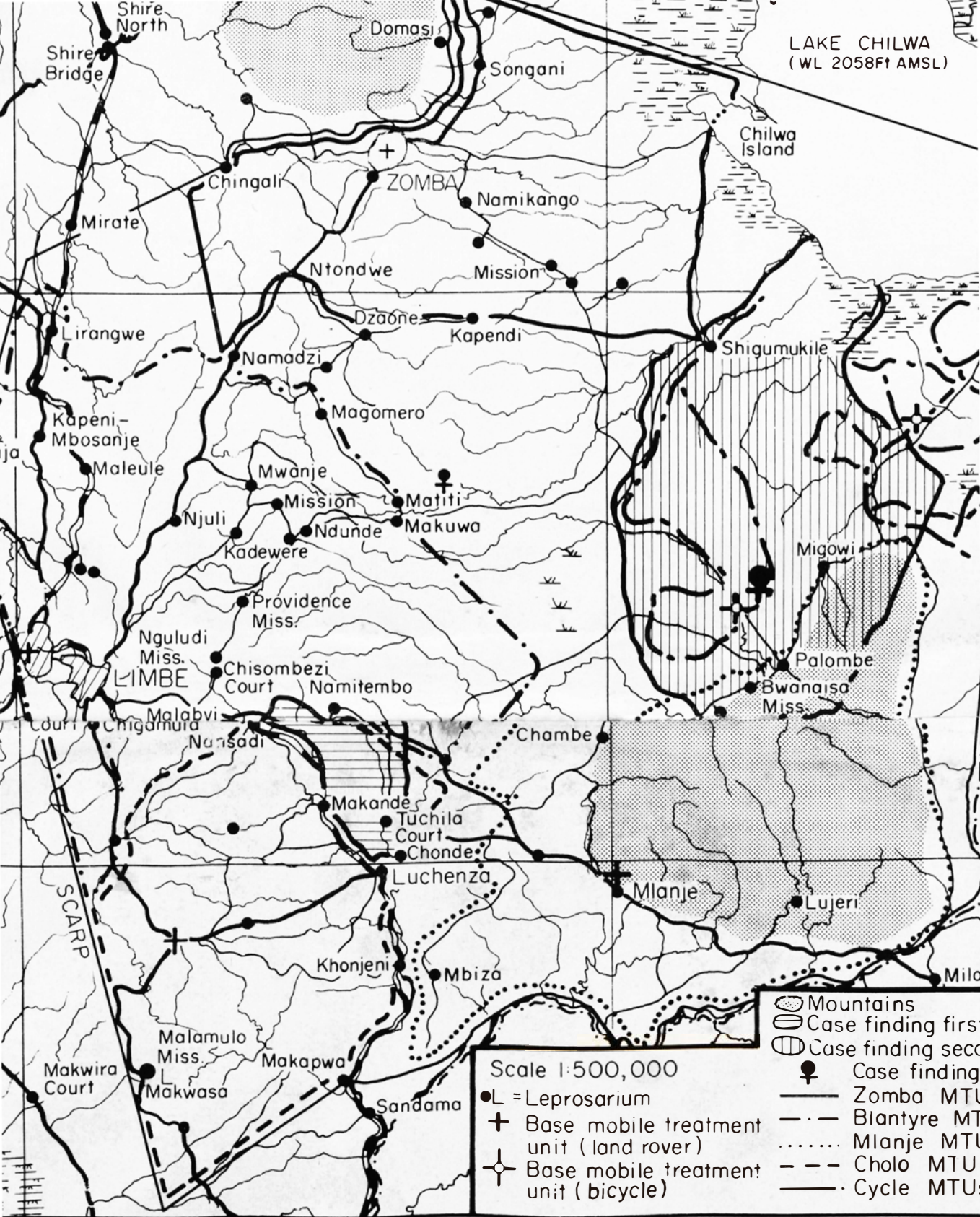


FIG. 1