

Leprosy and the Community

LEPROSY IN THE SUDAN GEOGRAPHICAL DISTRIBUTION AND PREVALENCE

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Introduction

Very little is known about the distribution and prevalence of leprosy in the Sudan. Accurate statistical data are not available because systematic attempts at case detection have been few and limited in scope. Most available information is derived from statistics from hospitals or leprosy colonies, giving the number of patients in them. Over 80% of patients inhabiting these colonies are severely disabled and burnt-out cases. As leprosy is still a highly stigmatizing disease among most of the tribes, it becomes obvious how misleading such statistics can be.

The geographical distribution of these colonies, and the number of patients in them, are nevertheless a relatively accurate index of the endemicity of the disease in those areas. I can say this with a reasonable degree of confidence as I have visited most of these areas and recorded the actual homes of the patients. Some exceptions, e.g. Khartoum, will be mentioned later.

Leprosy in the Northern Region

This vast expanse of land lies between latitude 12°N and 22°N. Its topography is either desert or semi-desert with few shrubs. With the exception of those living in towns, the inhabitants of this region are either farmers clustered along the Nile valley or nomads moving in the open with their sheep and camels.

The Region includes the whole of the Northern Province, the Red Sea Province, Northern part of Kassala, Kordofan, Darfur and most of Khartoum Provinces. It has been the general impression of all medical workers as far back as 1908 (Balfour, 1908) that leprosy is scarce in the region. This impression holds good up to the present day.

The Northern Province

Small foci of high endemicity are known to exist in this Province. A few cases were reported around Al-Daba and Merowi, and two other foci are located near Atbara and Shendi respectively. People in this Province are relatively sophisticated, and leprosy patients are either strictly confined or prefer to migrate further south to larger towns. Some go further south to join colonies in the highly

endemic areas. Only 25 patients, all hospital cases, are now recorded in this Province with a population of 1.2 millions.

Khartoum Province

The three main towns in this Province comprise the capital of the Sudan, its population totalling 1.4 millions. All leprosy cases live in these towns. Five hundred and seventy cases were recorded in 1972, almost all coming from the highly endemic areas in Southern Province of Kordofan, South Darfur and the three Southern Provinces. Very few indigenous cases are reported. Apart from patients seen in the dermatology clinics, two other main clinics for leprosy are worth mentioning.

- (a) The Church Mission Clinic. This is a mobile clinic supervised by an experienced expatriate sister assisted by a nurse with some leprosy training. They visited some 358 patients who live in different sectors of the town.
- (b) The Swiss Mission Clinic. Leprosy cases are seen as part of a general outpatient clinic run by an expatriate doctor.

Patients are seen weekly and receive their treatment regularly. A 24 bed leprosy ward is under construction in Khartoum hospital.

The Red Sea, Northern Kassala, Kordofan and Darfur Provinces

These can be regarded as leprosy-free areas.

Leprosy in the Central Region

This fertile clay land extends from the verges of the semi desert at 12°N latitude to the rich savannah at latitude 10°N. Except for the highlands along the Ethiopian border and some scattered hills, the land is flat and fertile, with agriculture and animal husbandry the main means of livelihood of the inhabitants. This region includes the Blue Nile Province, Southern Kassala, Southern Kordofan, Southern Darfur and a small part of Khartoum Province.

There are three areas of high leprosy endemicity in this region.

(a) *Southern Kordofan (The Nuba Mountains)*

The Nuba tribes inhabit these hilly areas. They are mainly farmers who cultivate small areas in the vicinity of their homes. The standard of living is generally low. Leprosy control activities in the Nuba Mountains were started in 1936 when three colonies were established (Sudan, 1936). In 1937 a further four colonies were constructed and by 1948 the total number of patients in the colonies reached 1651. No further progress was achieved, and some missionaries who were responsible for these colonies were sent out of the country for political reasons in the early 1960's. A survey was carried out in a small area in the Southern Kordofan by Dr Ali Daw Al-Biet in 1966. The prevalence of leprosy was recorded as 56:1000. A more detailed survey was started by Dr Hussein Hassan, but unfortunately it was not completed.

In 1972 there were four colonies and one outpatient clinic in this area. The total number of patients in the colonies was 2751 (Table 1). Over 500 patients living in these colonies receive regular rations from the government; the rest live nearby and come for treatment only. All these patients are looked after by medical assistants and nurses, none of whom have had special training in leprosy.

TABLE 1
Leprosy patients in colonies in the Nuba mountains, 1972

Place	In-patients	Outpatients
Umdorien	200	225
Nyakma	137	1073
Kawda	95	716
Abri	82	116
Hieban	—	106

(b) *Southern Blue Nile and Southern Kassala Provinces*

In the 1940's a colony was constructed in Roseris, Southern Blue Nile, and some 140 patients now live there. It is perhaps enlightening to realise that most of these patients migrated from Kordofan, while others come from other Provinces including the Northern Province.

Apart from the Colony there are two highly endemic foci. One of them is in the Ingesana Hills, 50 miles south of Roseris. A sample leprosy survey carried out in this area in 1952 revealed that there are 500-600 patients in this area. Touring this area in 1972 and visiting most of its villages I had the impression that the number of patients cannot be less than 800. The other focus lies in another hilly area in the south, about 40 miles south west of Kurmak. Most of the patients live with their relatives, and very few report to Roseris Settlement.

In Southern Kassala there is a colony in Gedarif. The total number of patients reported in 1972 was 25, the same figure as reported in 1928, more than 40 years ago.

(c) *Southern Darfur*

Darfur is the Province which borders the Republic of Chad which is well known for its high endemic level for leprosy. There are two colonies, one in Zalinki started in 1933 with 24 patients, the other in Genena. The number of patients in these colonies in 1972 was 165 and 80 respectively. Apart from these colonies, no leprosy control activity has been undertaken in this area.

Leprosy in the Southern Region

The Region lies between latitude 10°N and 4°N. It extends from savannah in the north into tropical jungle in the south, and comprises mainly the three southern Provinces. It is inhabited by a jumble of tribes. The Nilotics who are mainly nomadic live in the north and central part, while the other tribes who are mainly farmers and hunters live in the south.

Leprosy work was started relatively early in this region, especially in the Zande area where it was carried out in connection with the well organized sleeping sickness campaign. It seems clear that the medical workers engaged in sleeping sickness control encountered many cases of leprosy.

In 1926 the number of patients was estimated to be 900-1000 for Equatoria Province, with a similar number for Bahr El Ghazal Province. By 1928 seven colonies were established and by 1930 the total number of patients reached 8000. In a survey carried out in 1952 in a population of 27,000 of the Moru tribes the prevalence was 44:1000; 10.2% of the cases were lepromatous in type.

TABLE 2

Leprosy patients in colonies in Bahr El-Ghazal province, 1972

Place	No. of patients
Wau (Agok)	130
Raga	80
Rumbek	240
Yirol	—
Tonj	—

Unfortunately this organised work was suddenly interrupted by the disturbances which broke out in the Southern Region. Some of the patients fled to neighbouring countries; those who remained were confined to the colonies. In Bahr El Ghazal Province there are now five colonies, with numbers of patients as shown in Table 2. In Upper Nile Province there are two colonies, one in Malek with 24 patients and the other in Maban area with 20 patients. In Equatoria Province there were 390 patients in Lui colony. After the Addis Ababa agreement a large leprosy settlement was established by the German CARITAS in Baria Band for leprosy patients returning to their own areas.

Conclusion

In conclusion, very little has been done in leprosy control. The present data are only approximate and may sometimes be misleading. For future planning more precise information is needed. Any help from World Health Organisation or any country would be welcomed, particularly in the field of statistics and case detection. This would enable us to plan on a sound foundation and look forward to a better future, and so overcome the gloomy past which characterized the leprosy work.

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LEPROSY IN THE SUDAN

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With a limited national income and a surface area covering nearly a million square miles, the Sudan faces considerable problems in environmental health and the control of endemic diseases. Amongst the latter is leprosy, estimated by WHO to

affect 100,000 people, based on the 1966 population of 12,831,000. The population is now at least 16 millions, and in recent years some areas of high endemicity or hyperendemicity have been recorded by experienced observers. The leprosy control programme is still in the early stages of development, and factors such as poor roads and communications over vast distances, lack of transport, low population density, and limited funds for medical work generally have hindered progress in some provinces. Significant contributions are being made by Church Leprosy Relief, the Roman Catholic Church, the Swiss Government, and particularly by the German Leprosy Relief Organisation, who have started the construction of a leprosy training and demonstration centre in the south.

The leprosy control situation in the Sudan is described. Attention is drawn to the urgent need for some system of provincial and central registration of all patients, and for the collection of up-to-date statistical information not only from the 12 leprosaria, but also from all general hospitals and out-patient clinics in the country.

Leprosy in the Sudan has been described (Bechelli, 1970) as a serious public health problem, and in 1966, based on a population of 12,831,000 WHO estimated that there might be as many as 100,000 cases in the country.

A limited gross national income has resulted in small amounts of money being available for medical work (approximately 25 new pence per head per year), most of which – understandably – is absorbed by general preventive, curative and hospital services. The leprosy control situation has almost certainly been made even more difficult by the running down of missionary work in the North especially in Kordofan, and by the virtually complete withdrawal of missionaries from the South during disturbances in 1964. In recent years the Ministry of Health has welcomed aid from various outside agencies in their campaign against leprosy and the most significant development is that of the German Leprosy Relief Organization near Wau, in the southern Province of Bahr el Ghazal, where work has already started on a large leprosy training and demonstration centre. About 2 years ago, OXFAM received a request for practical help in the leprosy control programme, and the author was given the task of visiting the Sudan in order to obtain up-to-date information, with particular regard to statistics, training of personnel, transport, out-patient diagnosis and treatment, and the possibility of epidemiological studies.

Background Information

The Sudan is a vast, flat, hot country of clay plains, desert or duneland, with hills at the extremities. It is 10 times larger than Britain, with an area of nearly one million square miles – the largest country in Africa.

About 40% of the population are Arab, 20% central Nilotic, 10% Fur and other tribes of Darfur Province, and the rest Beja, Nubiyin and nilo-Hamitic. In the North, where over 2/3 of the people live, the feeling is Arab and Moslem, while in the three Southern Provinces of Bahr el Ghazal, Equatoria and Upper Nile, the people are Negroid or Nilotic, and there is a considerable ethnic, administrative and political boundary between the two regions. From about 2 million inhabitants at the beginning of the century, the estimated population is now over 16 millions; the pyramid of age distribution is broad-based, 5% being under the age of one year; 23% under five years; 50% under 19, 70% under 30, and only 1% over the age of 70. Until recently there were nine provinces; Blue Nile, Kordofan, Darfur, Kassala, Northern, Khartoum – all in the north; Bahr el Ghazal, Equatoria and Upper Nile in the south. A few months ago however, Kordofan, Kassala and

Blue Nile were all divided into two, and other subdivisions are in hand. Furthermore, the Ministry of Health has in some areas its own concept of Health Provinces, which do not necessarily correspond with political divisions. While certain roads leading out of Khartoum are good, most surfaces are of sand or mud, and liable to become totally impassable after the rains. There is a single track railway from Khartoum to the Northern Province; to the Red Sea; through Kordofan; to Darfur; into Blue Nile Province, and south to Wau in Bahr el Ghazal. It takes five days to get from Khartoum to Wau. Goods taken off ships in the Red Sea may take the better part of a year to get to the deep south.

Leprosy Statistics; Prevalence, Incidence

The enormous distances and problems of communication have made it difficult to collect accurate information on the total of registered patients in out-patient clinics or hospitals, though combined figures for in- and out-patients in leprosarria are available (see Table 1). Although the Vital and Health Statistics Division of

TABLE 1
Government leprosarria in the Sudan, April-May 1974, with approximated totals of in- and out-patients

Province	Provincial population ^a	Leprosarium ("colony")	Combined approximate total of in- and out-patients
Blue Nile	3,235,000	Roseiras	140
Darfur	1,735,000	Zalingi	165
		Genena	80
Equatoria	1,336,000	Juba (Luri)	700
		Bariabande	?
Bahr el Ghazal	1,463,000	Agok	214
		Rumbek	260
		Tong	174
		Raga	100
Kordofan	2,882,000	Om Durein	450
		Nyakma	1100
		Kawda	900
Approximate totals		12	4283

^a Based on 1965 census. From 2 million people at the beginning of the century the figure rose to over 10 in 1956, to over 15 in 1969, and to at least 16 in 1974. The annual growth rate is 2.8%. Provincial populations for 1974 are not yet available.

the Ministry coordinates figures on leprosy for annual and other reports, it is not routinely notifiable (nor is tuberculosis). Based on a population of 12,831,000, WHO in 1966 estimated 100,000 patients for Sudan, i.e. about eight per thousand, and subsequent observers (Bechelli, 1962; Laviron, 1971) have seen no reason to reduce this figure. Laviron drew attention to high rates in the Nuba mountains, with prevalences of 25 per thousand in some places, and to figures of 14 per thousand in limited case-finding surveys in various villages. The map in Fig. 1 shows other areas where a high incidence of leprosy has been recorded in the

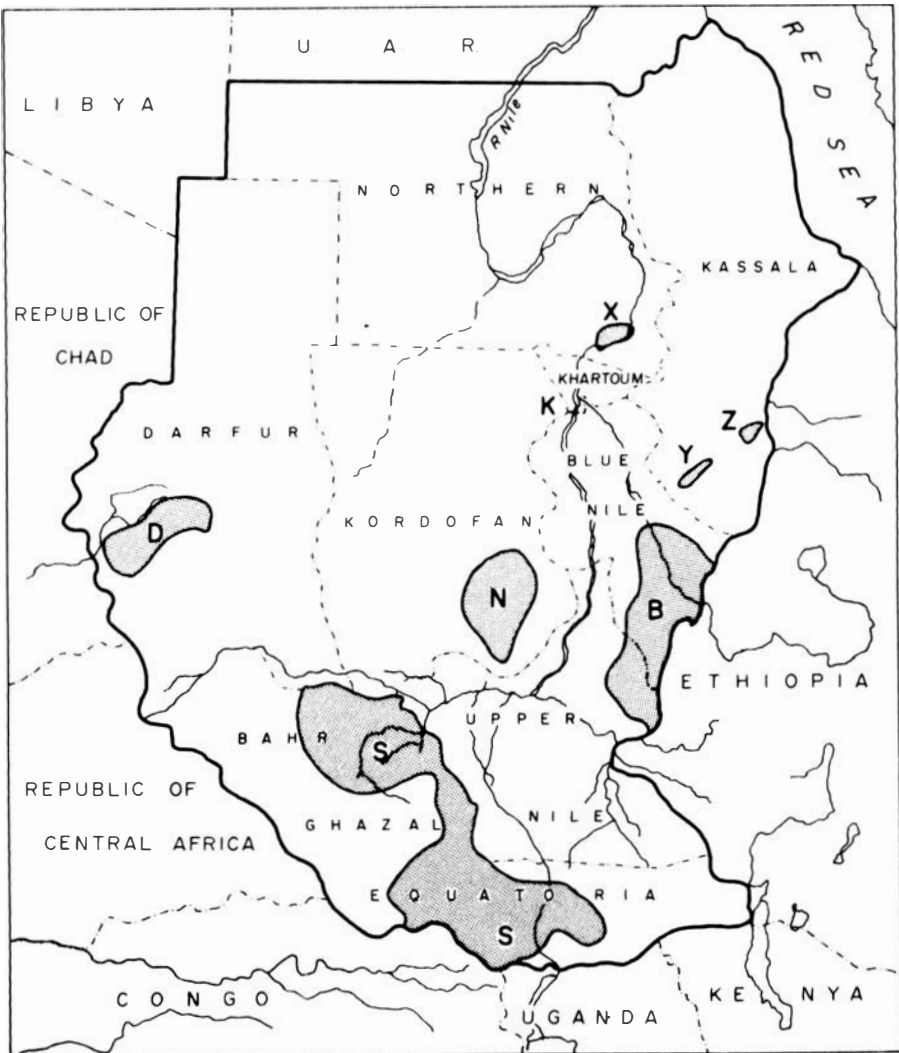


Fig. 1. The Sudan. (Department of Surveys, Khartoum; original scale 1:8 000 000). Nearly one million square miles in area, the country is bordered by—United Arab Republic, Red Sea, Ethiopia, Kenya, Uganda, Congo, Republic of Central Africa, Republic of Chad and Libya. K is Khartoum, the capital. The cross-hatching indicates areas where available evidence points to a significant incidence of leprosy. X, Y and Z are in Northern and Kassala Provinces, D in Darfur, B in Blue Nile, S and S in Bahr el Ghazal and Equatoria. N is the Nuba mountain area of Kordofan Province, where the highest incidence has so far been recorded.

past, or where new cases are continuing to occur. In common with experienced mission workers and all previous reports, doctors who have travelled the Sudan extensively agree that the most seriously affected area is in the Nuba Mountains of Kordofan Province (N).

Although the latest Annual Statistical Report (1971) from the Health Ministry gives figures mainly in the region of 1500 cases per year, it is the opinion of senior officials concerned with the interpretation of these returns that existing statistics are failing to reveal the true situation. This is mainly because a system of notification and registration of old and new patients has not yet been developed at district and provincial level, but also because too much emphasis has been given to in-patients in colonies, and their closely associated out-patients. Frequent movement of patients from one part of the country to another (for instance from Kordofan into Blue Nile, or from the southern province to Khartoum) has added to inaccuracies.

Structure of the Health Services in Relation to Leprosy Control

This has not changed substantially since the WHO assignments reports of Laviron (1971) and Wheate (1973). Virtually all districts are covered by hospitals and clinics which could effectively integrate leprosy out-patient diagnosis and treatment, but in practice there are serious problems related to low population density, bad roads and communications. Leprosy control is under the Rural Health and Endemic Disease Programmes in the Ministry of Health in Khartoum, where there is also a permanent WHO representative, and an office for the UNICEF combined smallpox-BCG inoculation programme. A National Plan for leprosy control was drawn up in 1972, after full discussion between the Ministry and all missionary and other agencies in the Sudan concerned with this disease. WHO has made a limited grant for consultancy, equipment and transport, and will supply a leprologist for the Leprosy Training and Demonstration Centre in the province of Bahr el Ghazal in the south, due to open in about two years from now. This centre, near Wau, the provincial capital, and only a few kilometres from the Government leprosarium of Agok, is at the stage of ground clearance at the time of writing. Despite some concern about rapidly mounting costs it could clearly develop as an important factor for the future of leprosy control in the Sudan. Apart from 48 hospital beds and a residence for semi-ambulatory patients, the plan includes facilities for out-patient treatment, physiotherapy, tailoring, carpentry, occupational therapy, repair and car workshop, and a leprosy assistant school. Residential accommodation for staff, students, guests and doctors is included. Other centres which have been constructed include (1) a 20-bed unit in the grounds of the Khartoum General Hospital, financed by the Swiss Government, now virtually completed. Although undecided as yet, it is thought likely that clinical responsibility will be shared between the dermatologists in an adjacent unit and Church Leprosy Relief; (2) a 20-bed unit at Rumbek in Equatoria in the south, a cooperation between the Catholic "Sudanaid" and the Government, where a group of sisters, trained at ALERT in Addis Ababa, are already at work. Apart from the wards, this unit will eventually include a doctor's house and out-patient clinic, with personnel and transport supplied by Sudanaid.

As regards general policy, the Ministry in Khartoum is insistent on priority for preventive, rural and environmental health programmes, and on their wish to follow WHO advice on leprosy control. While they have as yet to overcome many problems in the integration of leprosy work into general medical services, they have been able to follow up the oft-repeated policy (WHO, 1973) that "promotion of the training of general health personnel in leprosy control is receiving priority attention from WHO". A Medical Officer for Leprosy has been

appointed in the Ministry after a period of training in ALERT and in Uganda, three other Sudanese doctors have visited ALERT, and a surgeon has also studied there with a view to reconstructive surgery. In addition a number of mission sisters, one Catholic father, three male Sudanese nurses and a group of 10 medical assistants have also been trained either in ALERT, Karachi or Uganda.

Leprosy work in Khartoum and Omdurman

Church Leprosy Relief, in cooperation with the Abu Rouf out-patient clinics in Omdurman, now supervise the treatment of approximately 700 patients in Khartoum, Khartoum North and Omdurman. A Landrover is used to contact them at any convenient point or in "borrowed" clinic accommodation. They form a miscellaneous group, with a high percentage of deformity which has often attracted them to Khartoum and to professional begging. A surprising number originate from far-distant parts of the Sudan, including the deep south.

Provincial touring

Following discussion in Khartoum with the Ministry, WHO, UNICEF and mission personnel, visits were made to the Provinces of Kordofan, Blue Nile and Bahr el Ghazal with the main object of seeing out-patient facilities at first-hand while talking to doctors, medical assistants and others who might be handling leprosy patients, and paying visits to various leprosy colonies.

In all three provinces, there are adequate facilities for out-patient treatment, but distances from village to clinic either for the patient or the leprosy worker, together with the poor quality of roads, and the hazards of the rainy season make work difficult. Transport is in short supply; its integrated use for the prevention or treatment of several diseases at the same time has not yet been developed. In the south of Kordofan, 102 patients were examined in detail in the Government leprosarium of Om Durein. On a purely clinical assessment, 39 of these showed no evidence of clinical activity, had had long periods of in-patient treatment and were unclassifiable at the time of examination; 22 were lepromatous, obviously very long-standing, and apparently without any clinical activity; 17 had active lepromatous, 11 active borderline and 13 apparently inactive borderline disease. Serious disablement, including blindness, was common. From Om Durein in the south, via the district hospital at Kadugli, it is possible to make a loop through the Nuba Mountain area, returning to the more central district hospital at Dilling. This takes 13 hours and is mainly on roads which are bad in the dry season, impassable in the wet. At one remarkably remote point on this loop is the Government leprosarium of Nyakma, founded by the Sudan United Mission in 1939, and staffed by a group of expatriate missionaries until 1962, after which Government took over responsibility. Now to a considerable extent self-supporting and autonomous, figures are difficult to interpret in respect of (1) in-and out-patients (large numbers of the latter live in close proximity and their status is vague); (2) the numbers of healthy adults and children in or near the colony; (3) those who are officially entitled to "full" as against "supplementary" diet from the Government.

Laviron in 1970 found 258 out-patients as against 872 patients "in the settlement", but Ministry figures virtually reverse these; 137 in-patients and 1073 out-patients. A combined total of about 1100 may be near the mark. Many

patients have been in Nyakma for well over 10 years. Marriages are common; in 1970 there were 25 births and 81 healthy children, and today the figure for babies, infants and children may be nearer 200. The clinical situation here as regards classification, activity/inactivity, fitness for discharge to out-patient treatment, release from control, prevention and correction of deformity, needs detailed clarification, but it is clear that its remote situation, (it is completely cut off during the wet season) and the long periods of residence and marriages of so many patients will create peculiar problems. Clearly the correct yearly incidence of new cases and the lepromatous rate must be determined for this whole area as soon as possible. In Blue Nile Province, district hospitals and clinics were visited en route to Roseiras leprosarium where 114 patients were examined. Fifty eight showed no clinical activity, but were unclassifiable at the time of examination, 20 were long-standing, long-treated lepromatous patients without any clinical activity; 5 had well-settled, inactive borderline disease; 1 active tuberculoid; 9 active borderline and 21 active lepromatous. Deformity including blindness was widespread and severe in degree. In Bahr el Ghazal, the Government leprosarium of Agok, about 6 km from the provincial capital of Wau, and only a few kilometres from the German Leprosy Relief Organisation Project, had 112 patients available for clinical examination. Of these 63 showed no activity but were unclassifiable at the time of examination, 24 had apparently inactive lepromatous disease, and had been treated for periods as long as 10-15 years; 6 had inactive borderline disease; 15 active lepromatous and 4 active borderline. Again deformity of all kinds was widespread and advanced. Other leprosarria ("colonies") in the Sudan are shown in Table 1, where figures have been approximated between those in Ministry reports and other sources.

BCG inoculation in the Sudan

There is a combined smallpox-BCG campaign run by UNICEF, based on the Ministry of Health in Khartoum. Although the coverage for smallpox has been excellent (no known case in the country for over 15 months), that for BCG has not developed as planned, due to lack of vaccine and practical difficulties in giving both inoculations at the same time. About one million doses have been given in the six northern provinces, but in the three southern provinces the coverage was described as "negligible".

Discussion

Information gained during this visit confirms the impression of previous observers that there is indeed a serious leprosy problem in the Sudan, and that its magnitude and distribution are—almost urgently—in need of accurate clarification. The Ministry understands this well, one of their recent documents on the subject including the introductory statement: "Hence there is no accurate statistical data about the disease." In the Sudan this could be more important than usual, for its immense area of nearly one million square miles, coupled with limited resources in money and transport for leprosy work make it essential to give priority to areas of known high endemicity. Indeed a study of all previous reports, backed by the opinion of doctors who are experienced and widely travelled in the country,

suggests there are large, sparsely populated areas where it may be unrealistic to develop leprosy control services at all. However existing information from the known endemic foci, and from the 12 Government leprosaria is in need of much greater development as regards classification, activity/inactivity, length of treatment and disability grade. Intensive reassessments are needed to decide what proportion of leprosarium "in-patients" in fact need to stay any longer in an institution. At the same time out-patient treatment should be expanded so that the considerable costs of these colonies may be reduced. Plans are actively under discussion in Khartoum with the Ministry and Church Leprosy Relief for setting up a central Registry, which would involve the notification of every individual patient, with appropriate details. Reviewing the present leprosy control programme at the time of writing, it is difficult to see any more important step than the urgent development of this Registry so that the total picture may be defined. Incidental to this, information on the tribal and regional incidence of leprosy in the Sudan would surely be of epidemiological interest.

In the training of personnel it may well be that the total of those who have already been abroad for courses is adequate for the present needs, and that caution must be exercised to avoid the return of trainees, full of enthusiasm and new knowledge, to conditions which are—unavoidably—deficient in transport or such important details as clinical record cards, alternative drugs to Dapsone, drugs for the treatment of various forms of reaction, dressings for neuropathic ulceration and damage, plaster of Paris and footwear. It could well be that staff already trained will meet the needs satisfactorily until the opening of the training centre at Wau within the next few years. In the Government leprosaria however, it seems that day-to-day nursing, particularly in the field of prevention and correction of disabilities, together with social and physical rehabilitation, is difficult to meet. Should it be possible to reconcile with current political views, there is little doubt in the writer's mind that the introduction of small groups of medically trained mission sisters to some of these colonies would be of the greatest benefit.

In summary, the Sudan does indeed have a serious problem in leprosy, with particular difficulties related to its huge size, low population density, limited transport and poor roads. However the seeds of a constructive approach have been sown and if the impetus already shown by various foreign agencies can be followed up, matters may well improve. "One of the important conclusions to emerge from the Tenth International Leprosy Congress in Bergen, Norway in August, and marking the centennial of the discovery of *Myco. leprae*, was that, where an effective case-detection and case-holding programme has been developed, the total number of patients and the annual rate of detection of new cases has been reduced." (The Work of WHO, 1973.)

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*These are numbered WHO assignment reports, and should not be regarded as publications.