

The Importance of Onchocercal Skin Disease

Report of a multi-country study

by

The Pan-African Study Group
on Onchocercal Skin Disease



TDR



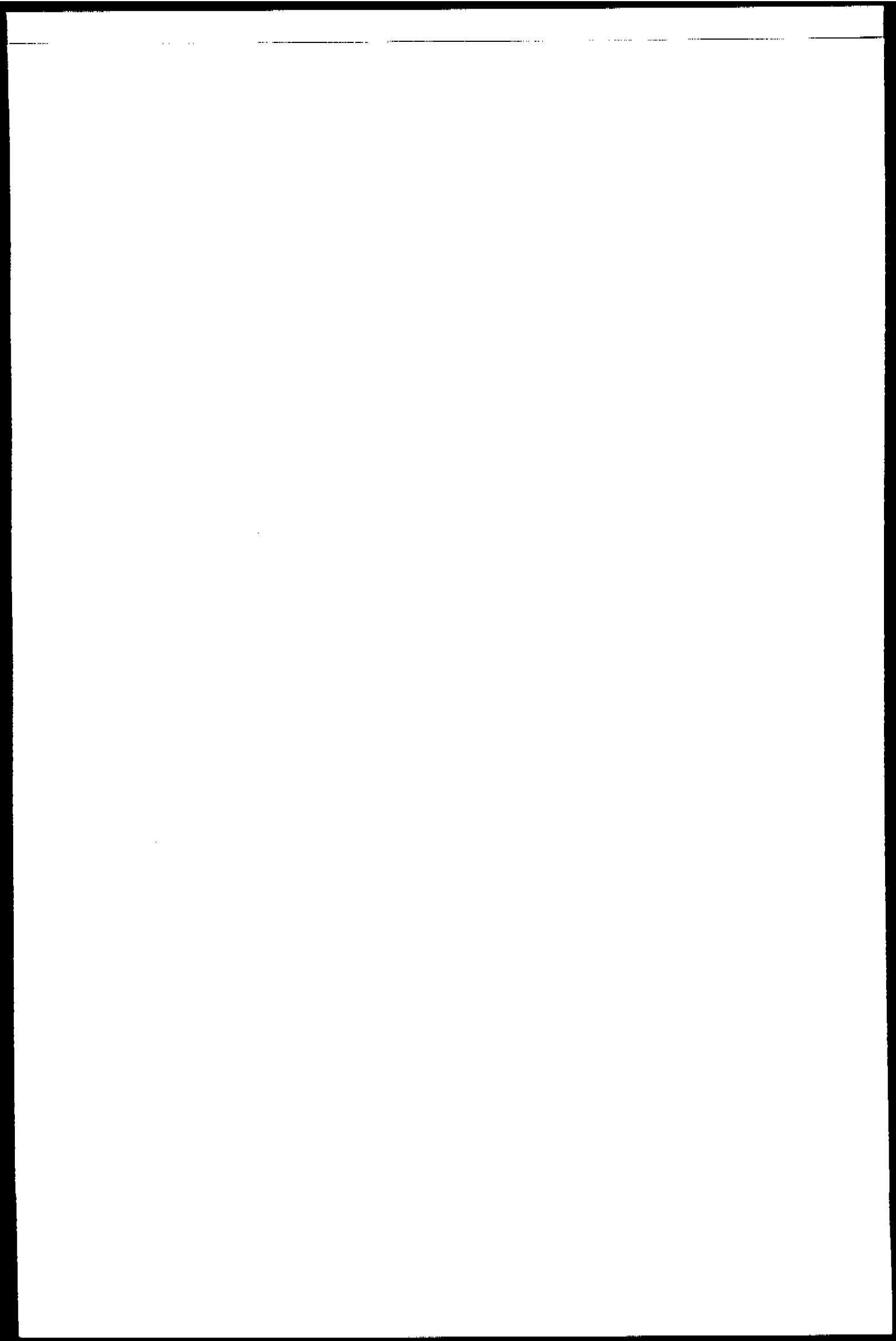
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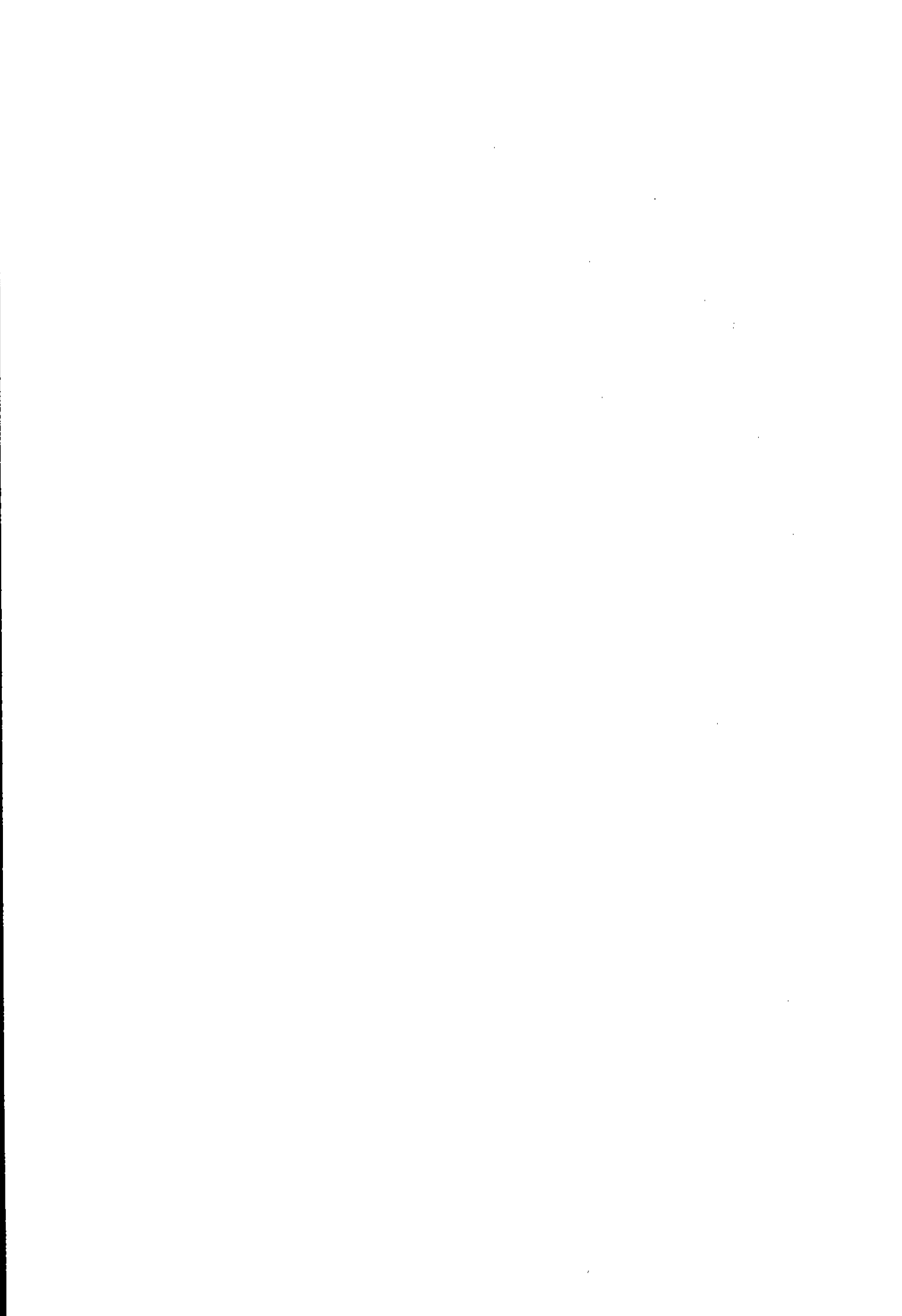
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STUDY DESIGN AND METHODOLOGY

RATIONALE

Onchocerciasis remains a serious public health problem in Africa where it affects some 17.6 million people. However, the epidemiological pattern of onchocerciasis varies considerably between geographical zones, probably because of the existence of parasite strains of different pathogenicity. In the West African savanna, the parasite strains are highly pathogenic to the eye and the infection is a significant cause of blindness. Onchocercal blindness has always been given high priority as a public health problem and major efforts have been undertaken by endemic governments, international organizations and non-governmental organizations to try and control the disease as a public health problem in the savanna areas of Africa. To date, major successes have been achieved by the Onchocerciasis Control Programme in West Africa (OCP) in controlling the disease through vector control, and elsewhere several control programmes have been launched using large scale ivermectin treatment in areas where blindness is common.

However, an estimated 8.9 million infected people (over 50% of all infected) live in areas where onchocercal blindness is not common, but where onchocercal skin disease may be highly prevalent. In most of these areas there are currently no onchocerciasis control programs, partly because of the low priority given to skin disease. Nevertheless, the disease burden and the public health importance of onchocercal skin disease has never been properly studied and is therefore not known. To address this issue, a multi-country study was undertaken in 1994 to determine the public health and psycho-social importance of onchocercal skin disease and to provide an objective basis for rational planning of onchocerciasis control throughout the African region.

STUDY OBJECTIVES

The study had two main objectives, namely:

1. To determine the prevalence and clinical severity of onchocercal skin disease in hyper-endemic communities in Africa.
2. To determine the psycho-social importance of onchocercal skin disease in these communities.

STUDY DESIGN

The study was a multi-centre/multi-country study involving 8 collaborative centers in hyper-endemic onchocerciasis foci in West, Central and East Africa. Four centers were in Nigeria (Awka, Calabar, Enugu and Ibadan). The other four centers were in Tanzania and Uganda in East Africa, Cameroon in Central Africa and Ghana in West Africa.

In each study area a standard study protocol was used which involved a cross-sectional parasitological and dermatological survey in selected hyper-endemic communities and in one

non-infected community in the same area, selected as control. Furthermore, a psycho-social study was undertaken in selected subgroups of this population using a semi-structured interview as the principal study method. Other social science methods, such as focus groups, key informant interviews and participant observation were also used, partly to help design the appropriate format for the structured interview.

The study aimed to compare villages which were hyper-endemic for onchocerciasis and non-affected control villages. Study villages were selected on the basis of the results of Rapid Epidemiological Assessment using nodule palpation in adult males or, where available, the results of skin snip surveys. Hyper-endemic villages were defined as those with a prevalence of microfilariae (mf) of more than 60%, or a prevalence of nodules in adult males of more than 40%. Control villages had to have a prevalence of mf in adults of less than 10%.

METHODOLOGY

Skin Examinations

Skin examinations were performed by physicians using a recently developed clinical classification and grading system for the cutaneous changes in onchocerciasis¹. The main categories of onchocercal skin disease defined were Acute Papular Onchodermatitis (APOD), Chronic Papular Onchodermatitis (CPOD), Lichenified Onchodermatitis (LOD), Atrophy (ATR) and Depigmentation (DPM). Skin lesions were further graded according to i) severity ii) clinical activity in terms of itching and scratch marks and iii) extent of distribution over the body. Information on itching was obtained at the beginning of the examination when each person was asked whether they currently suffered from troublesome itching, and, in case the answer was positive, whether the itching regularly disturbed their sleep. These questions on itching were masked between questions on general health problems and specific questions on whether they currently suffered from headaches, from chest pain or from stomach ache. All findings were recorded on a standardized form.

Inter-observer variation study

The eight clinicians involved in the study met together for a week of intensive teaching and clinical demonstrations to familiarise themselves with the onchocercal skin disease classification system. At the end of the week a formal inter-observer variation study was conducted on 40 patients consisting of individuals with normal skin, onchocercal skin disease and non-onchocercal skin disease. Kappa values were used to calculate the level of agreement for each clinician compared with the trainer. (N.B. For perfect agreement between 2 observers the kappa value=1, for no agreement kappa=0; by convention a kappa value >0.6 indicates acceptable agreement). Results of the inter-observer variation study revealed kappa values >0.6 for all clinicians for APOD, CPOD, DPM and for most observers for ATR. Acceptable results were also obtained for all observers for the presence of nodules. Insufficient number of cases of LOD were available for full validation of LOD and for non-onchocercal skin disease.

¹Murdoch ME, Hay RJ, Mackenzie CD, Williams JF, Ghalib HW, Cousens S, Abiose A, Jones BR. A clinical classification and grading system of the cutaneous changes in onchocerciasis. *Brit J Dermatol* 1993; **129**: 260-9.

The clinical findings were entered onto computer using EPI INFO 5 software package and results analysed using EPI INFO 5 and SPSS/PC+ for WINDOWS.

Assessment of the Psychosocial Aspects of Illness

This study has developed an innovative approach to the study of the illness burden of tropical diseases. Epidemiologists typically refer to illness burden with reference to morbidity and mortality, especially the latter. Such concepts are especially attractive because they are easy to measure and compare. Recent social science contributions to international health have focused on the role of economic indicators, as exemplified by the conceptualization of the Disability-Adjusted Life-Year (DALY) by the World Bank. The emphasis on mortality and economics, however, may fail to capture the experience of suffering associated with tropical diseases, which constitutes a major aspect of illness burden in many settings, independent of mortality and easily measurable economic impact.

Concepts developed by medical anthropologists have attempted to characterize the experience of illness from the point of view of those who have it as a complement to professional concepts of biomedical disease. The explanatory model theory has guided much of this research and motivated development of the Explanatory Model Interview Catalogue (EMIC) in previous studies of leprosy and other medical and psychiatric disorders². The EMIC was adapted and used in this research to study the experience and meaning of onchocercal skin diseases among those directly affected by them.

The EMIC elaborates elements of an explanatory model with reference to local analogues of professional concepts. For example, patterns of distress refer to the problems associated with illness, complementing possibly overlapping signs and symptoms that facilitate diagnosis; perceived causes explain the disorder in terms based on locally defined concepts, which also may be similar or dramatically different from professional theories of etiology. Preferences for help seeking and treatment indicate local ideas about what should be done, complementing a professional treatment plan.

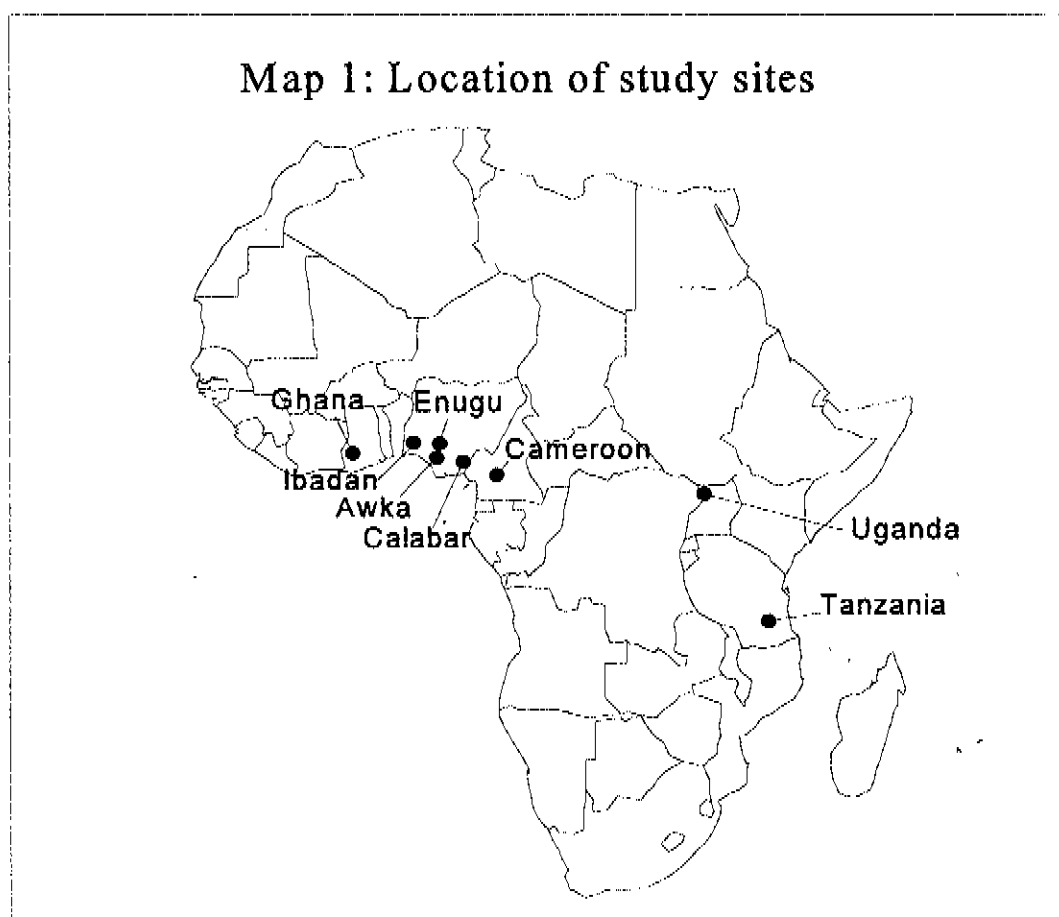
At a TDR-sponsored workshop in Calabar, Nigeria, in June 1993 investigators participating in this multi-centre study met and adapted the EMIC to study onchocercal skin diseases. They also planned focus group and in-depth interviews. In January 1994 the group met again at a second workshop in Ibadan to revise this instrument based on experience from qualitative methods and pilot testing. Two instruments that resulted from this process were to be used to study the experience of onchocercal skin diseases among 100 onchocerciasis-affected persons at each of the participating sites and to inquire about community ideas and attitudes, based on questions about typical cases depicted by a vignette and photograph. Fifty interviews with non-affected persons were planned in the onchocerciasis-affected hyper-endemic study sites and another 50 in the hypo-endemic control sites where clinical-epidemiological surveys had also been planned. At these workshops the investigators also learned principles of qualitative data management, including the use of a computer program to assist in this task, TextBase Alpha.

²Weiss M.G. et al. (1992). *Br. J. Psychiatry* 160, 819-830

Findings from this study of the illness burden of onchocercal skin disease that will be presented in this report focus on patterns of distress and symptoms of these disorders, illness-related stigma, and efforts to obtain help and relief from the suffering associated with these conditions. Discussion of these findings will also indicate how the methods developed in this research may be applicable to efforts to characterize the illness burden of other tropical diseases, comparisons among diseases and across sites, and changes in the illness burden that may result from various interventions or in association with social and ecological changes.

STUDY SITES

The study was carried out in eight sites in Africa (see map 1). Four of the sites were in Nigeria, namely, Awka, Calabar, Enugu and Ibadan. There was one site each in Ghana, Cameroon, Uganda and Tanzania. All of the sites lie in the Rain Forest Zone of West, Central and East Africa. Ghana, Nigeria, Cameroon and Uganda lie close to the Equator. Tanzania, is more southerly situated, but the study villages were located on a mountainous range with tropical rain forest.



AWKA

The study was carried out in Nkwelle-Ezunaka town in Oyi Local Government Area of Anambra State, Nigeria. The town has eight villages. The River Nkisi which runs through the town forms a breeding focus for *Simulium damnosum* flies. The village, Oze, which lies along the River bank was used as the endemic village, whilst Odoata which is farthest from the River was used as the control village. Odoata is about 5 km away from Oze.

Both the control and endemic villages were identified by Rapid Assessment Methods using Nodular Rates. Because of the total lack of baseline epidemiological data in Oze, the prevalence was confirmed by the determination of the mf prevalence in the population above 5 years of age.

The villagers are mainly subsistence farmers. Oze is a homogeneous community with practically

no migration. The language is Igbo. The high rate of depigmentation observed in Oze is indicative of long-standing onchocerciasis. Also observed was an unusually high reporting of poor visual acuity even among the younger age groups.

CALABAR

Ningane and Aningeje, the two endemic villages, are in Akamkpa Local Government Area. They have a population of about 5000 people. In addition to the Kwa Falls, the area has rivers Ebe and Edu flowing through it. The area is also blessed with vast virgin forests and oil palm plantations. These features have attracted a large percentage of Ibibio immigrants who live there to undertake farming and palm fruit harvesting. Over the years these immigrants have dominated the indigenous population - the Ejagham - both economically and demographically. The population is stable because 90% of the migrant population are permanent immigrants who have lived continuously in the area for more than ten years. Akansoko, the control village with a population of about 3000 people is in Akpabuyo Local Government Area. It is blessed with secondary forests and oil palm plantations, and it has also a large number of Ibibio immigrants. In both areas, Efik and Ibibio languages are the main media of communication. The endemic and control villages are about 50 km and 20 km from Calabar town respectively.

CAMEROON

The study was carried out in the Monatele district, located in the middle valley of the Sanaga River which provides *Simulium* breeding sites all along its course, as the main river system of the country, flowing in a southerly direction. Onchocerciasis is hyper-endemic and severe in the basin of the Sanaga river. Prevalences of positive skin snips range from 37.0% to 93.2%; CMFL varies from 1.3 and 81.3; blindness rates greater than 2% are found. The classical savanna distribution pattern has been described in the area. The study villages Nkolakok, Nkolmeyos, Nkolassa, all hyper-endemic for onchocerciasis constituted the endemic communities, located within 10 to 15 km from the Sanaga river. Efok, the control community was located 20 km away from the endemic communities site. Two of the endemic communities (Nkolmeyos, and Nkolassa) were made up respectively of two settlements.

The population in the study community was stable and homogenous, and consisted of one major ethnic group, Eton (99%), predominantly Christian. The average size of the family was 7 ± 4.58 (i.e. average number of people living in the same household). Over 80% of the study participants either had no formal education (31%) or had not completed primary education (51%). Most study participants had no formal jobs, claiming to be subsistence farmers (57%), while a small percentage held salaried jobs (< 1%). Seventy three percent of the population live in mud houses, 25 % in cement-finished houses. 95% of houses are covered with iron corrugated sheets. Health facilities in the area included one district hospital in Nkolakok and two rural health centers.

ENUGU

The study area, Nike is near Enugu, the capital of Enugu State. Nike (06° 31'N; 07° 31'E) falls within the forest - savanna - mosaic vegetational zone in eastern Nigeria. Agriculture provides employment for over 85% of the population, and both men and women are actively involved in

the farming activities. All the inhabitants are Ibos and the language spoken is Igbo. All year round rivers which drain the area include the Idodo, the Iyoku and the Ekulu rivers. Members of the *Simulium damnosum* complex have been identified breeding in all three rivers while the adult flies have been caught biting in almost all of the Nike area even on farmlands.

Most of the houses in the villages selected for this study consist of mud walls/floors and thatch roofs and the five villages have a population of about 3,300. The population is quite stable and over 95% of persons inhabiting the villages are indigenous. Administratively, each of the study villages has a traditional ruler, a council of elders and age-grades. The age-grade consisting of men between the ages of 30 - 40 years is usually the ruling age-grade and assists the traditional ruler and the council of elders in the governance of the village.

GHANA

The study took place in the Aowin-Suaman District of the Western Region of Ghana. The research team resided in the area during the study period. Five communities were involved: the pilot study site of Nyankomam, the endemic villages of Jensuu, Achimfo, Abochia and the control village of Kramokrom. They all lie at a radius of less than ten miles from Enchi town. The population comprised about 3,500 and 850 at the endemic and control villages respectively. They are mostly ethnic Brussa (Aowin) but the vast majority can speak the Wassa dialect of Twi, the language of interview. Health facilities in the area included the district hospital at Enchi and three PHCs. Mobile Child welfare clinics are held periodically at villages by Community Health nurses. In addition the area has its traditional healers.

IBADAN.

The study communities consisted of *Papa* and its surrounding villages used for the pilot study, *Elesu* village used as the control community, and *Jago* and its surrounding villages which were the endemic communities for this study. The Papa communities are located in Iwo local government area (LGA) of Osun state, some 40 kilometres north of Ibadan, and along the Oba river, a tributary of the Osun River. Elesu is situated some 30km north of Ibadan in Lagelu LGA of Oyo state, of which Ibadan is the capital. Its population by a 1987 de jure census was 766. Jago is located 30km east of Ibadan on the north-eastern border of Ono-area LGA of Oyo State, on the banks of the Osun/Asejire River. A de jure census of the communities at the commencement of this study showed the population to be made up of 1917 people. Jago and 7 other surrounding villages constituted the endemic communities of the study. The microfilariae skin snip prevalence was 45.4% overall in the endemic communities, ranging from 31.3% to 66.7% in the 8 individual villages. This prevalence was 14.0% in the control Elesu community. Nodular prevalence in adults over 50 years in the endemic and control villages were 28.4% and 7.1% respectively.

The endemic communities have no modern health services except for a weekly health clinic run at Jago by public health nurses from the University College Hospital (UCH) in Ibadan. Elesu also has no modern health services except for a monthly self help community health clinic they hold with the help of community physicians from the UCH at Ibadan. However, for both communities, various health services are available from the bigger towns and villages 8 to 15 km from these villages, on tarred roads for Elesu and on very bad and often unmotorable roads for the Jago and related communities.

TANZANIA

The study was conducted in the villages of Bwakira Chini (Endemic) and Kiziwa (Control) in Morogoro region. Onchocerciasis has been a long-standing problem for the endemic village and people often relate it to witchcraft and other traditional issues. The population of permanent residents of the two villages was 2555 (1394 in the endemic village and 1161 in the control village). The area has two rainy seasons. The main rainy season is from March to June and the second with fewer rains during the months of October and November. Ninety five percent of the population are peasants and the main food crops are maize, rice and millet whilst simsim is produced as a cash crop. Just before the main rainy season people tend to move to their farms which are mostly situated near the river Bwakira in readiness for preparation of their farms. They spend most of their time in their farms until after the harvesting in August when they return to their homes. During the farming season the population increases as more people move to the village for the purpose of farming and tend to move away after harvesting. Neither village has health care facilities but they share these facilities with the nearby villages (i.e a Health Centre 8km from Bwakira and a dispensary 12 km from Kiziwa). The study was done during the main rainy season.

UGANDA

The study took place in Nebbi District in the North Western region of the country. The population of the endemic communities was 9,621 and that of the control village 1,863. The study in the endemic communities was conducted at 3 large centres where members of 8 villages gathered for clinical examinations and interviews. In the control village, examinations and interviews were conducted at one centre. The mf prevalence in the endemic population was 70%, and that in the non-affected village, less than 10%. Nodule prevalence in the hyper-endemic villages was 92% and that in the control village, 23%.

There are one mission hospital and two health centres in the endemic area. The control village is 2-3 km away from the only District hospital. Interaction with elderly people in the study area suggest that onchocerciasis has been with that community for a very long time. Despite the fact that the community in this area is close to the Uganda-Zaire border, the population has been stable in terms of mobility and homogeneity. However, the problem of onchocerciasis cuts across the border and this may complicate the control of the disease. At the time of the study a few cases of plague were admitted both in the District Hospital and the Mission Hospital. The problem of plague is perennial in the area, and the number of admissions to the two hospitals increases between June and August each year during the rainy season.

CLINICAL AND EPIDEMIOLOGICAL RESULTS FOR SEVEN SITES

POPULATION EXAMINED

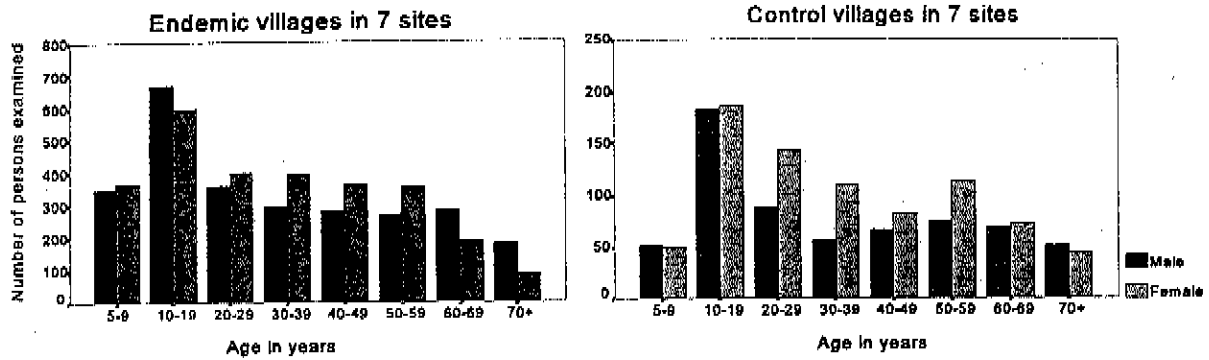
A total of 6,910 persons above the age of 5 years were clinically examined in seven study sites (the clinical data for the eighth site, Calabar, were not available for analysis). Out of these, a total number of 5,459 (79%) were examined in the endemic villages while 1,451 (21%) were examined in the control villages (see table 1 below).

Study site	Endemic villages			Control villages		
	no. of villages	no. examined	Prevalence of nodules (range)	no. of villages	no. examined	Prevalence of nodules (range)
Awka, Nigeria	1	752	5.9	1	248	1.6
Monatele, Cameroon	7	862	26.8 - 76.9	1	219	9.1
Enugu, Nigeria	5	808	22.3 - 52.9	0	0	N.A.
Enchi, Ghana	3	767	39.8 - 67.2	1	252	6.3
Ibadan, Nigeria	3	751	5.6 - 22.7	1	253	5.1
Morogoro, Tanzania	1	749	57.9	1	256	2.7
Nebbi, Uganda	8	770	14.4 - 69.1	3	223	5.5 - 6.7
Total	28	5459	5.9 - 76.9	8	1451	1.6 - 9.1

According to the study protocol, each team was to select highly endemic villages and non-endemic control villages from the same area, and to examine some 750 people from the endemic villages and about 250 people from the control village. In reality it proved nearly impossible to find true control villages within the same area and all the villages selected as control were in reality hypo-endemic villages with a nodule prevalence between 1.6% and 9.1%. The "endemic" villages showed a very wide range of endemicity with the nodule prevalence ranging from 5.9% to 76.9%. This proved fortunate as it allowed a detailed analysis of the relationship between the prevalence of different skin manifestations and onchocerciasis endemicity. In the analysis of the clinical data, therefore, the division between "endemic" and control villages has not been rigidly maintained and an analysis by endemicity level has often been used instead. Furthermore, the control village in Enugu had a high endemicity level with a nodule prevalence of 22.3% and was therefore included in the group of endemic villages in the analyses where this grouping was used.

Figure 1 shows the distribution of the examined population by age and sex in the endemic villages and in the control villages. Compared to the normal age distribution of rural communities in Africa, there is an under representation of adults between the age of 20-40 years, and this effect is particularly marked among males in the control villages. In both the endemic and the control villages there were more women examined than men.

Figure 1: Examined population by age and sex



SKIN LESIONS

Figure 2 compares the overall prevalence of palpable onchocercal nodules, the prevalence of any onchocercal skin lesion and the prevalence of non-onchocercal skin lesions in the endemic and the control villages. The prevalence of onchocercal skin lesions was much higher in the endemic villages. There was much less difference in the prevalence of non-onchocercal skin lesions, but the prevalence was still significantly higher in the endemic villages. However, this is mainly an artifact due to the results for Enugu where there was a high prevalence of non-onchocercal lesions in all villages (see Figure 4), while there was no control village for that study site. After exclusion of Enugu, the prevalence of non-onchocercal skin lesions is 18.9% in the endemic villages and 16.5% in the control villages, a difference which is only of borderline statistical significance ($P=0.05$). The control villages were not free of onchocerciasis as can be seen from the prevalence of nodules which is about 5% in the control villages combined.

Fig. 2: Nodules and skin lesions

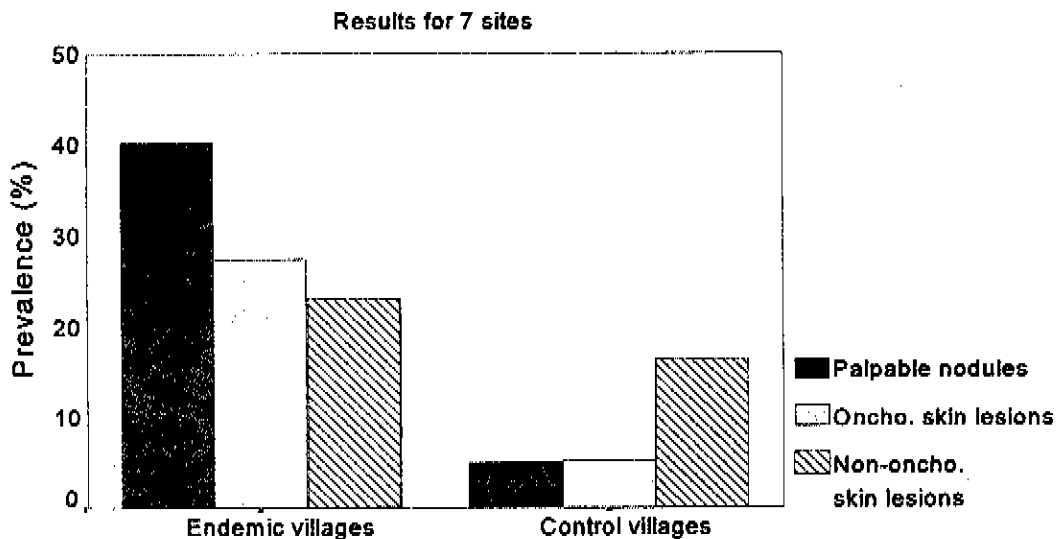


Figure 3 shows the prevalence of onchocercal skin lesions in each study site. In all sites the prevalence of onchocercal skin lesions is significantly higher in the "endemic" villages compared to the control villages. It should be recalled that there are no control villages for Enugu in the analysis.

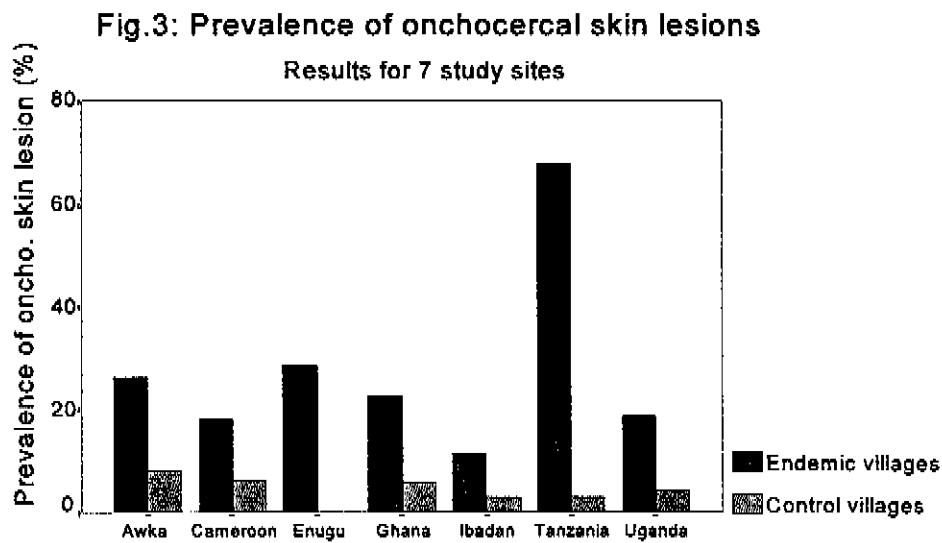


Figure 4 shows the prevalence of non-onchocercal skin diseases in the seven study sites. The prevalence varies significantly between sites with the highest prevalence being observed in Enugu, possible because the clinical examiner of this team was an experienced dermatologist. Per site, however, there was very little variation between the endemic and control villages. Again, note that there are no control villages in Enugu.

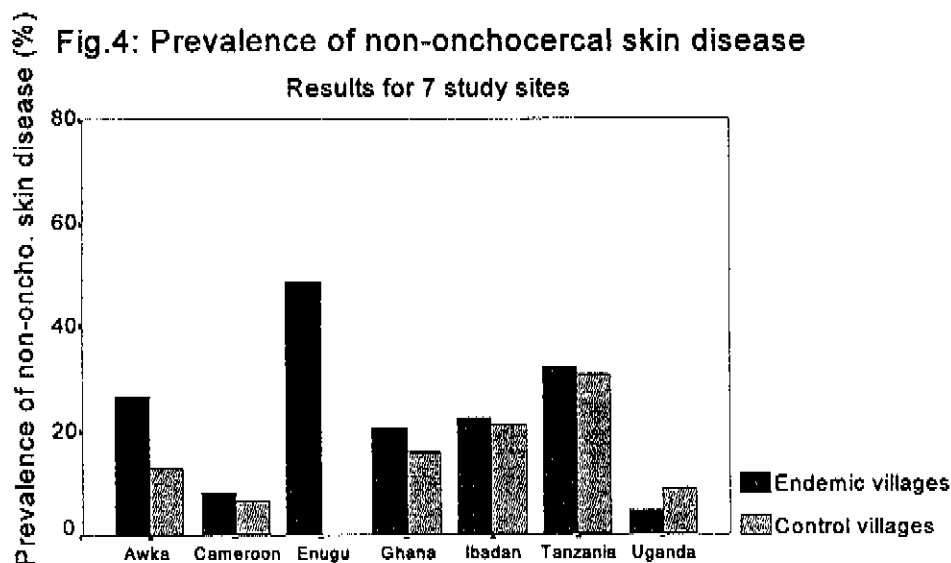
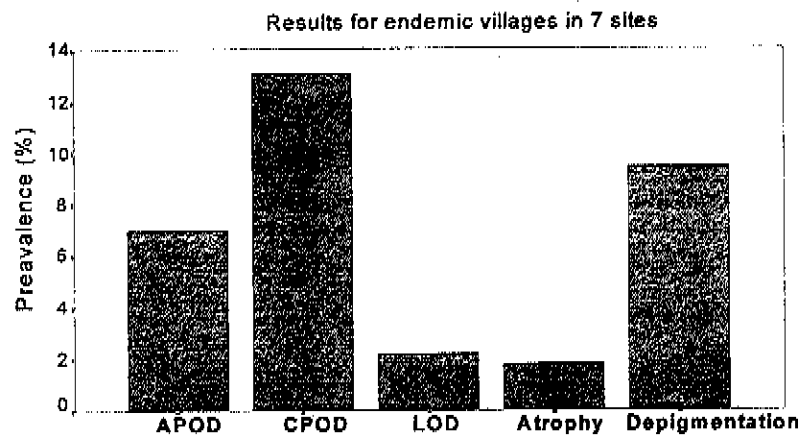


Figure 5 shows the overall prevalence of the four clinical morphological types of onchocercal skin lesions in the endemic villages of the seven study sites. The commonest type is Chronic Papular Onchodermatitis (CPOD) which affected 13.1% of the population above 5 years, followed closely by Depigmentation (DPM) (9.5%), Acute Papular Onchodermatitis (APOD) (7%), Lichenified Onchodermatitis (LOD) (2.2%) and Atrophy (ATR) (1.8%).

Fig.5: Onchocercal skin lesions



SKIN LESION BY AGE AND SEX

The prevalence of each of the onchocercal skin lesions is given below by age and sex.

Fig. 6: Acute Papular Onchodermatitis [APOD]. As is shown in this figure, APOD was most prevalent in the younger age groups and the prevalence tends to decrease with age.



Fig.7: Chronic Papular Onchodermatitis [CPOD]. This condition is least common below the age of 10 years. The prevalence of CPOD rises rapidly with age till the age of about 20 years and levels off thereafter. The pattern is similar for both males and females.

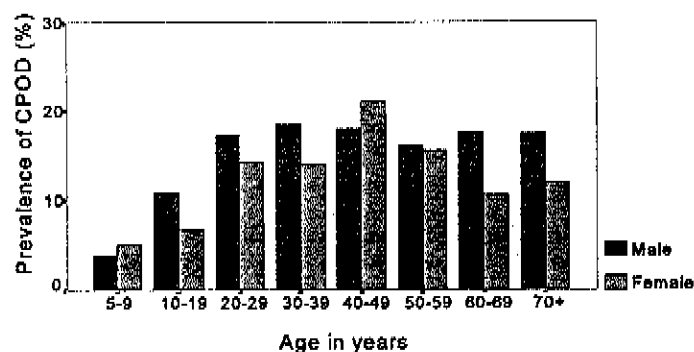


Fig. 8: Lichenified Onchodermatitis [LOD]. The prevalence of this condition was generally low. The age-specific pattern was similar to that observed for CPOD with an increase of the prevalence of LOD till the age of 20 years and a levelling off thereafter among males and some decrease among females.

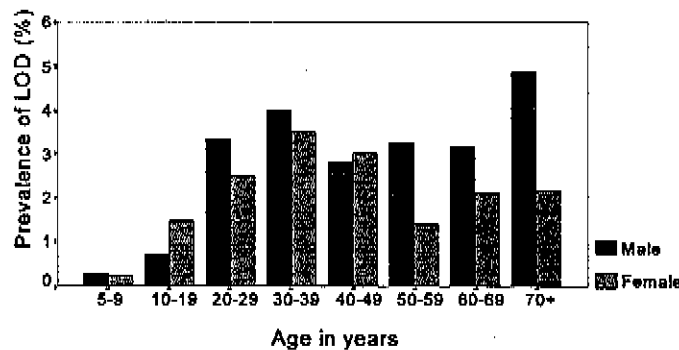


Fig. 9: Atrophy [ATR]. The prevalence of this condition was also low. However, it should be recalled that the diagnosis of ATR was made only below the age of 50 years. Given that the prevalence rises with age and that atrophy in the older age groups is not included by definition, the overall prevalence of atrophy will grossly underestimate the true prevalence of onchocercal atrophy of the skin. Below the age of 50 years, the age-specific trend in the prevalence of atrophy is very similar to the trend for depigmentation (see Fig.10) with the prevalence of atrophy on average being equal 0.74 times the prevalence of depigmentation. Extrapolation of these results suggests that the true prevalence of onchocercal atrophy may be in the order of 7% of the total population instead of the prevalence of 1.8% reported in Figure 5. Only very few cases of atrophy were identified in the control communities.

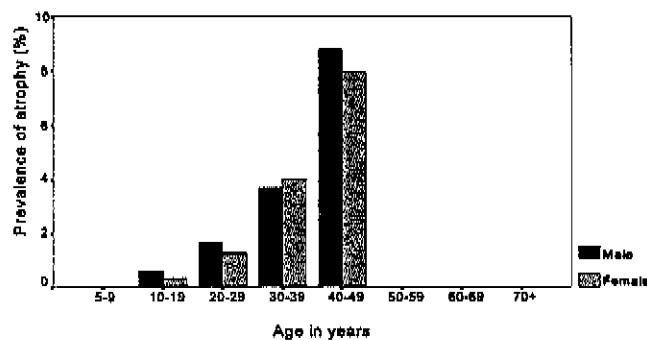


Fig. 10: Depigmentation [DPM]. This included pale-brown leopard skin and complete depigmentation or typical leopard skin. DPM was rare below the age of 20 years and affects mainly the older age groups. There were very few cases of DPM in the control communities.

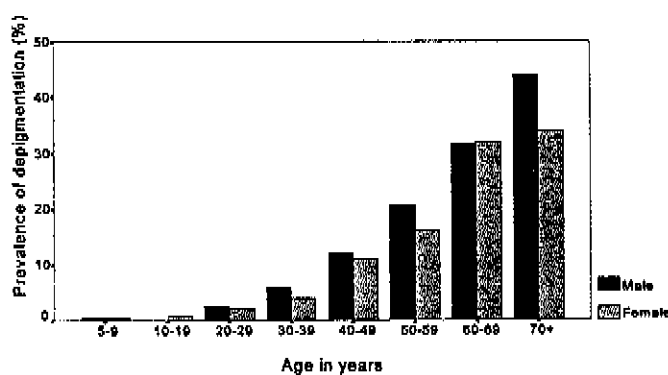
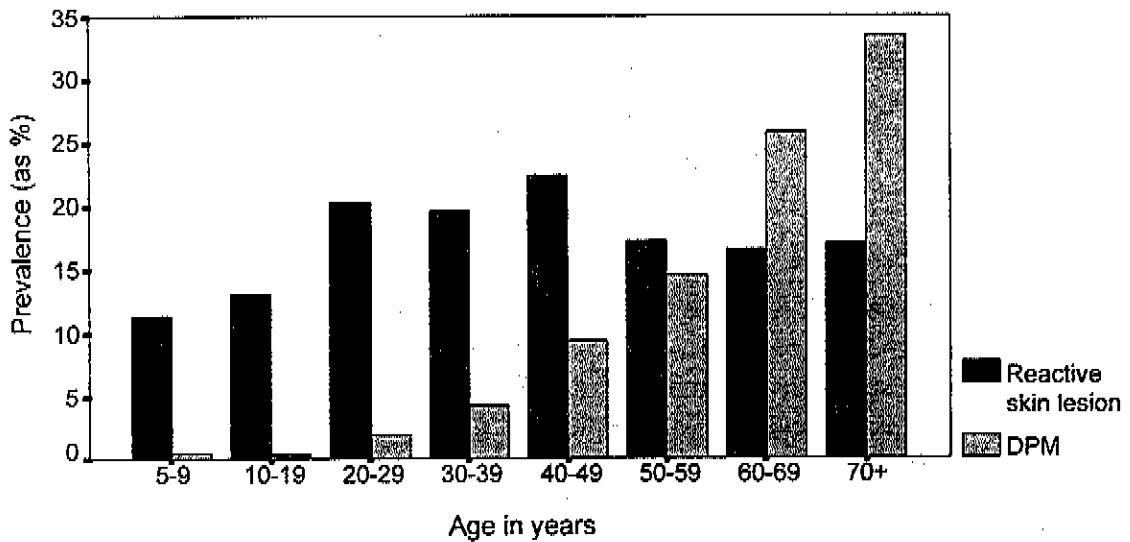


Figure 11 compares the age-specific prevalence of reactive skin lesions (APOD, CPOD and/or LOD) with the prevalence of depigmentation. While depigmentation mainly affects the older members of the population, reactive skin lesions are common in all age groups. The highest prevalence of reactive skin lesions is found between the ages of 20 and 50 years.

Fig. 11: Onchocercal skin lesions by age
Results for endemic villages from 7 sites



TROUBLESOME ITCHING

Fig 12 shows the prevalence of troublesome itching in the endemic communities by age and sex. The prevalence of itching was lowest among the under-10 year olds, rising till it more or less plateaus from the age of 20 years onward; a pattern similar to that of reactive skin lesions. There is no significant difference in the prevalence of troublesome itching between males and females.

Fig.12: Troublesome itching by age and sex
Results for endemic villages from 7 sites

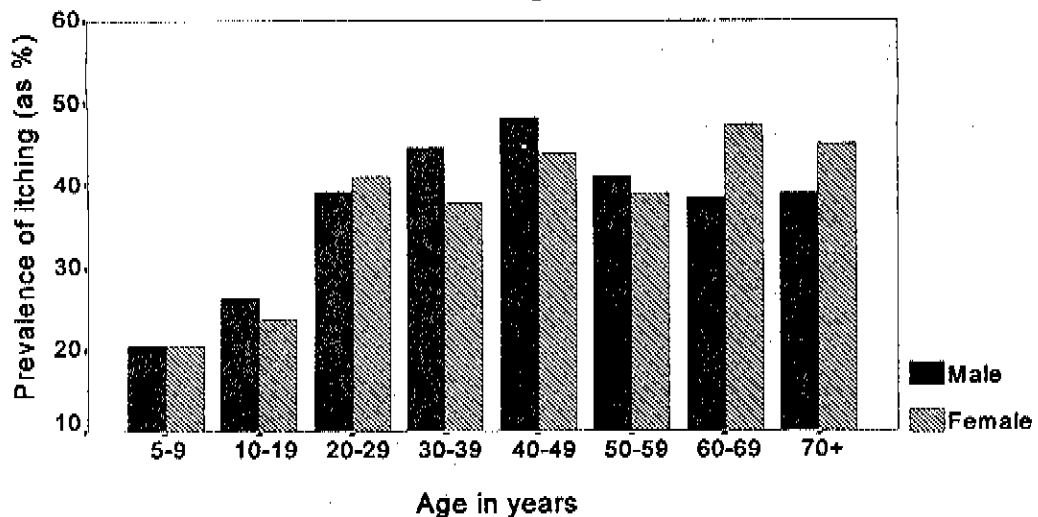


Fig 13 shows the relationship between the prevalence of troublesome itching and palpable onchocercal nodules in the endemic and control communities in all the study sites. Each point on the graph represents one endemic village or a group of small endemic villages located in the same area and with a similar prevalence of onchocerciasis infection as determined by skin snip examination. The relationship shows a strong and statistically significant correlation ($r=0.75$; $p<0.001$), and this suggests that most of the reporting itching can indeed be attributed to onchocerciasis. The prevalence of troublesome itching was also significantly correlated to the prevalence of reactive skin lesions (APOD, CPOD and LOD).

Fig.13: Prevalence of troublesome itching by endemicity

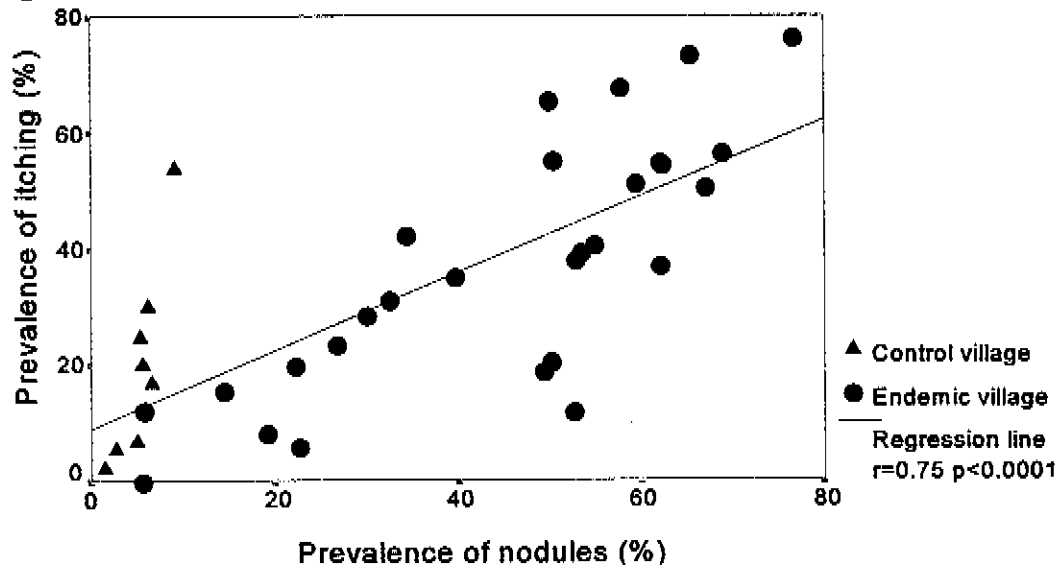


Table 2 shows the prevalence of troublesome itching in four sub-groups into which the examined individuals have been divided on the basis of the presence or absence of onchocercal and non-onchocercal skin lesions. Viewed across, it can be concluded that non-onchocercal skin diseases would appear to account for only a very small portion of reported troublesome itching. The lowest prevalence of troublesome itching (19.6%) occurs in the group of people who are neither affected by onchocercal skin lesions nor by non-onchocercal skin disease (the top left box of the table); while non-onchocercal skin disease increases such itching by only a small margin from 19.6% to 20.7% as shown in the top right hand box. The lower row shows the very high prevalence of troublesome itching among persons with onchocercal skin lesions. Among those without non-onchocercal skin disease, there is a dramatic increase in the prevalence of trouble-

Table 2: Prevalence of troublesome itching in relation to onchocercal and other skin lesions

		Non-onchocercal skin disease	
		Absent	Present
Oncho-cercal skin lesions	Absent	19.6 %	20.7 %
	Present	70.5 %	75.2 %

some itching from 19.6% in those without onchocercal skin disease to as much as 70.5% in those with onchocercal skin lesions. However, the additional occurrence of non-onchocercal skin disease increases the prevalence of itching only just a little again to 75.2%. These results provide another strong indication that it is onchocercal skin disease which is the main factor responsible for troublesome itching in these communities and that other skin diseases play only a minor role. It should be noted that the itching in the group without any skin lesion may also be largely due to onchocerciasis infection according to the results in figure 13.

The above results were confirmed in a multivariate logistic regression analysis (see Table 3) which showed that at the individual level, the presence of reactive skin lesions was the most important risk factor for troublesome itching (Odds Ratio 18.3), followed by the presence of palpable nodules (Odds Ratio 4.6). After correcting in this multivariate model for the other variables listed in the table, there was no statistically significant relationship between troublesome itching and depigmentation, while the risk of troublesome itching was slightly lower in females compared to males, and only slightly higher in persons who had other skin disease.

Table 3: Odds ratios for the risk of troublesome itching according to different risk factors (all odds ratios adjusted for the other risk factors listed)

Risk Factor	Odds Ratio	95% confidence interval	
Age			
< 20 years	1		
≥ 20 years	1.65	1.42	1.91
Gender			
Male	1		
Female	0.91	0.85	0.97
Palpable nodules			
Absent	1		
Present	4.63	4.05	5.29
Reactive skin lesion			
Absent	1		
Present	18.30	15.19	22.04
Depigmentation			
Absent	1		
Present	0.88	0.70	1.10
Other skin disease			
Absent	1		
Present	1.29	1.10	1.51

SKIN LESIONS BY ONCHOCERCIASIS ENDEMICITY

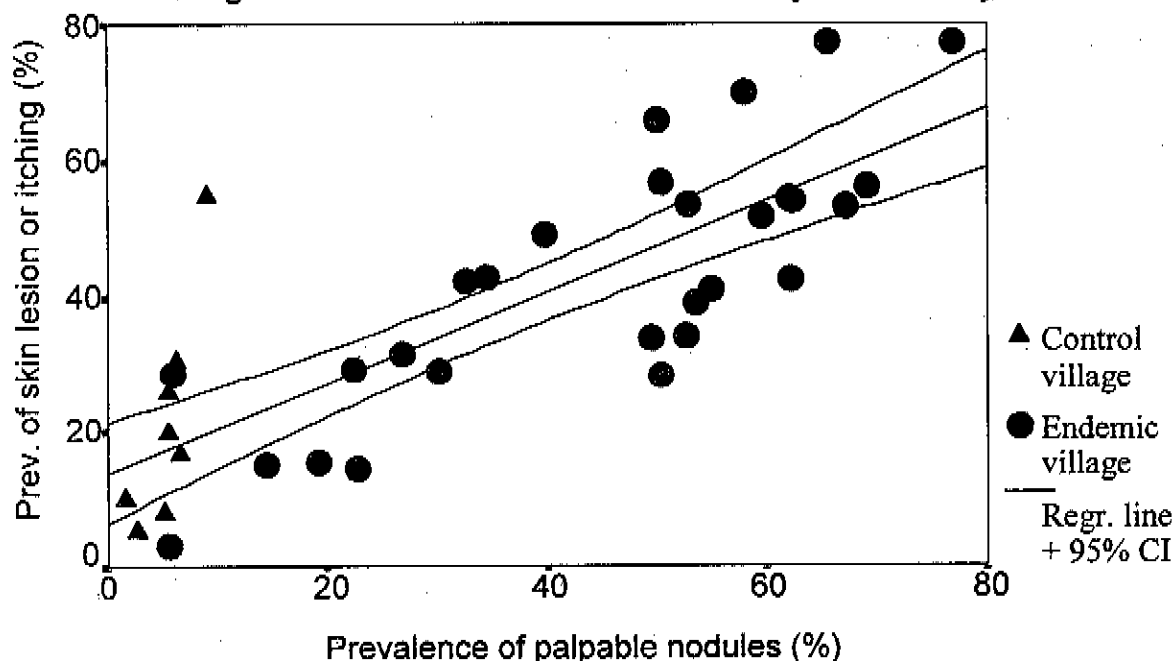
Table 4 shows the correlation between the prevalence of different skin conditions and the level of onchocerciasis endemicity of the community as measured by the prevalence of palpable nodules. The prevalence of most of the onchocercal skin conditions shows a statistically significant correlation with onchocerciasis endemicity. Among the onchocercal skin lesions, the correlation was stronger for reactive skin lesions than for depigmentation. Both the prevalence of any onchocercal lesion and the prevalence of troublesome itching showed a very strong correlation with endemicity, with correlation coefficients of 0.56 and 0.75 respectively (see also Fig. 13).

Table 4: Correlation between the prevalence of various skin conditions and the level of endemicity as measured by the prevalence of palpable nodules

Skin condition	Overall prevalence of skin condition (%)	Correlation between prevalence of skin condition and prevalence of palpable nodules	
		Correlation coefficient (r)	Significance level
APOD	5.8	0.20	P=0.254
CPOD	10.9	0.38	P=0.024
LOD	1.8	0.53	P=0.001
Reactive skin lesion	16.8	0.42	P=0.010
Atrophy	1.4	0.37	P=0.027
Depigmentation	7.9	0.34	P=0.045
Leopard skin	4.3	0.28	P=0.098
Any of the above skin lesions	22.8	0.56	P<0.001
Troublesome itching	31.7	0.75	P<0.001
Any of the above skin lesions +/- troublesome itching	38.1	0.80	P<0.001
Any other (non-onchocercal) skin lesion	21.9	-0.05	P=0.762

The highest correlation coefficient was obtained for the prevalence of onchocercal skin lesions and troublesome itching combined ($r=0.8$). The relationship for this important prevalence, which can be regarded as a composite index of the burden of onchocercal skin disease, is shown in Fig.14 below.

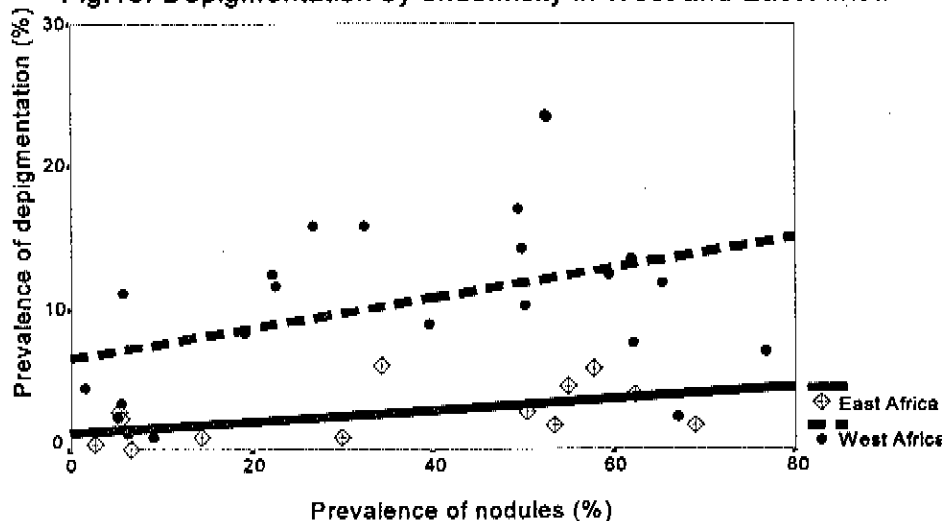
Fig.14: Onchocercal Skin Disease by endemicity



Depigmentation by endemicity

Depigmentation was not strongly correlated with the level of endemicity. However, a striking difference was observed between the East African and West African study sites in the relationship of the prevalence of DPM with endemicity. For all levels of endemicity, DPM was much more prevalent in West Africa than in East Africa.

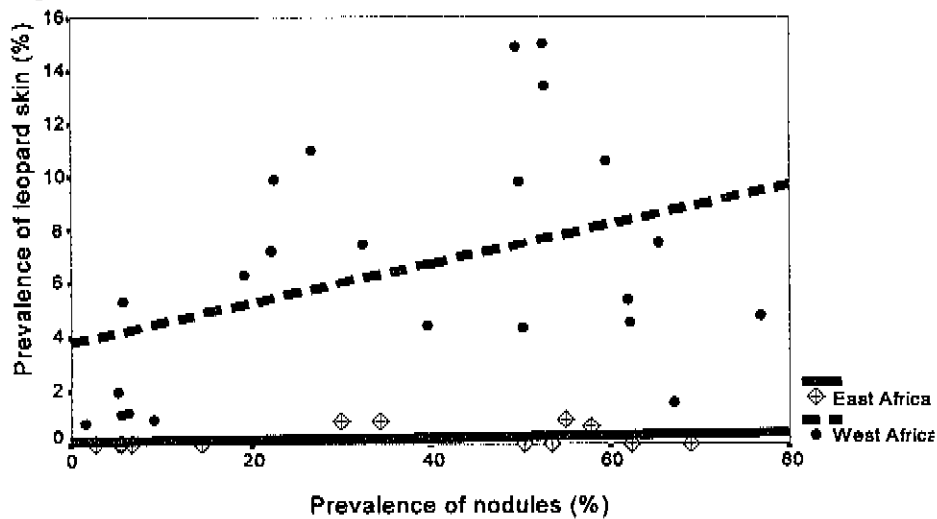
Fig.15: Depigmentation by endemicity in West and East Africa



The East-West difference was even stronger for Leopard Skin, which affected some 6%-10% of

the population of the hyper-endemic villages in West Africa, but which was virtually non-existent in East Africa even for very high levels of endemicity.

Fig.16: Leopard skin by endemicity in West and East Africa



CONCLUSIONS

Over 30% of the population in the endemic communities had onchocercal skin lesions. The most prevalent among them are chronic papular onchodermatitis (affecting 13.1% of the population), acute papular onchodermatitis (7%), and depigmentation (9.5%).

- There exists a strong correlation between the prevalence and severity of onchocercal skin disease and the level of endemicity in the community.
- More than half of the population of hyper-endemic populations is suffering from troublesome itching as a result of onchocerciasis.
- Troublesome itching is closely related to reactive onchodermatitis. Non onchocercal skin disease contributed very little to troublesome itching in the endemic communities.
- The prevalence of troublesome itching showed a strong correlation with the level of endemicity of the community ($r=0.75$, $p<0.001$).
- Reactive skin lesions and troublesome itching are common in all age groups with the highest prevalence being observed between the age of 20 and 50 years.
- There was a significant difference between the prevalence of onchocercal depigmentation in East and West Africa. Prevalence of onchocercal depigmentation, especially Leopard Skin, was very prevalent in West Africa but rare in East Africa even for high levels of endemicity.

ONCHOCERCAL SKIN DISEASE SYMPTOMS AND THEIR MEANINGS

Introduction

Although diseases are typically characterized by sign, symptoms and pathology, symptoms are not necessarily disease specific. Criteria based on these factors provided the basis for the epidemiological component of the study, but a complementary aim also considered the experience and impact of onchocercal skin diseases.

Both affected and non-affected were interviewed using semi-structured interviews to determine local meanings of symptoms, associated stiffness, and patterns of help seeking to find relief. The results of this study were based more on the experience of the affected persons themselves, an "emic" perspective, most of whom are illiterate rural dwellers, rather than the clinical evaluation of professionals, a so-called "etic" perspective..

Method

Respondents were asked a set of three types of questions including open-ended questions about what is troubling about the conditions (these generate spontaneous symptom reports), how it has affected their lives, which of the symptoms reported were considered most troubling for the affected; and if not mentioned in prior queries, additional probes about itching and the appearance of the skin.

The symptoms elicited can be categorised as: mentioned or emphasised. The meaning of emphasis may differ from person to person or could be culture specific but there are certain broad indicators of emphasis that can be said to be self-evident and thus serve as criteria for the determination of emphasis. These include the use of emphasisers, intensifiers, repetition, similes, voice clues, non-verbal indicators etc. The above distinctions between spontaneous responses, those based on probing and those derived from comparison of several symptoms or between emphatic and non-emphatic responses are necessary as the responses carry not the same significance.

The Significance of Itching

The study established that itching was the most salient symptom across sites followed by skin appearance, fatigue, joint-bone pain, headache etc. Respondents also mentioned a variety of other symptoms that were coded as Others. The latter included body pains, defective vision, abdominal problems to mention a few; of these vision stands out as a symptom perceived by respondents at all sites to be associated more directly or indirectly with the conditions in question.

Responses obtained from all three questions, i.e. the open-ended question, the probe and the comparison to establish most troubling symptom, lead to the same conclusion about itching, which was seen as the most important. Itching was mentioned or emphasised by 91.3% for reactive skin conditions and 72.9% for DPM. It was adjudged to be the most troubling by 59% of reactive skin cases and 41.5% for DPM cases. No other symptom comes close to these levels of onchocerciasis. Affected respondents across sites however appear to be divided on which one of the other symptoms is the next most salient symptom by mention. For example appearance, fatigue, and joint-bone pain had aggregate scores of 40.2%, 40.1%, and 40.3% respectively for

the two main categories of skin lesions together, but the actual frequency of mention or emphasis differ between respective conditions and sites. We see a runner up only when respondents were asked about the most troubling symptom. They placed skin appearance next to itching by an aggregate frequency of 9.9% mentions as the others now pale into insignificance.

The clear conclusion that emerges is that to the affected itching is by far the most important symptom of onchodermatitis conditions and symptom and the disease become synonymous to the affected. There is indeed evidence for this. In the Ghana site the importance of itching is further underscored by various terms, such as *ahokeka*, (body itch), *me ho kekame*, (my body itches), which have been mentioned by some respondents as names for reactive skin lesions. Furthermore even at sites where an onchodermatitis condition may not be referred to simply as "itching" the terms for some onchodermatitis diseases have been explained to either mean itching or to derive their justification from itching. For example, one DPM Ugandan case, like many others there, called his condition *gwenyu* ".because of scratching" and a number of people with reactive skin lesions did the same, calling their condition "*Ayila yila* because of persistent itching". In Ibadan we are told that "People call it *narun* or *ako kokoro*: anybody that has itching constantly .."

Site, Gender, Lesion and Symptom Reportage

The question remains whether site, gender, and type of lesion affect reporting of symptoms. The tables below provide answers to these questions. Gender is not a strong factor as far as those with reactive skin lesions are concerned. However women tend to report itching more than men. Most sites return high frequencies of mention for itching and Ibadan scored 100% for both sexes. The lowest scores are from Tanzania. In Cameroon there is a high concern for skin appearance for both sexes and scores are much higher than the average. Ghana, and Tanzania lie at the bottom with lower scores. Women again are more concerned about skin appearance than men except for Tanzania and Enugu where it is the reverse. To put the sites in the picture we reproduce below a fully tabular representation of the statistics.

Table 5: Frequency of Symptoms of Reactive Skin Disease Mentioned by Affected Persons (%)

SITE	SEX	ITCHING	APPEARANCE	INSOMNIA	FATIGUE
Awka	Male	90.6	62.5	28.1	37.5
	Female	96.4	85.7	28.6	35.0
Cameroon	Male	95	90.0	30.0	25.0
	Female	100	97.1	32.4	21.6
Calabar	Male	93.3	66.7	20	53.3
	Female	100	77.5	45	47.5
Enugu	Male	80	66.7	13.3	53.3
	Female	95.7	56.5	39.1	78.3
Ghana	Male	89.7	49.7	13.8	2.6
	Female	96.3	66.7	15.8	0.0
Ibadan	Male	100	70	60.0	70.0
	Female	100	80	30.0	50.0
Tanzania	Male	79.4	48.6	16.2	29.7
	Female	75.0	38.9	8.3	22.2
Uganda	Male	93.9	71.4	65.3	67.3
	Female	100	88.9	75.0	80.6

Table 6: Frequency of Symptoms of Depigmentation Mentioned by Affected Persons (%)

Site	Sex	No.	Itching	Appearance	Insomnia	Fatigue
Awka	Male	20	50	0.0	5	65
	Female	20	70	45	5	65
Cameroon	Male	21	100	85.7	28.6	61.9
	Female	21	100	90.5	33.3	66.7
Calabar	Male	17	76.5	52.9	41.2	58.8
	Female	16	87.5	56.2	43.7	43.7
Enugu	Male	27	63.0	44.4	22.2	74.1
	Female	6	66.7	33.3	33.3	83.3
Ghana	Male	15	66.7	73.3	6.7	0.0
	Female	13	84.6	46.2	31.8	0.0
Ibadan	Male	32	56.2	63.5	41.6	62.5
	Female	23	91.3	73.9	43.5	47.8
Tanzania	Male	17	85.8	52.9	17.6	58.8
	Female	9	77.8	33.3	22.2	55.6
Uganda	Male	11	82.8	90.9	54.5	45.5
	Female	4	100	75.0	75.0	100.0

Table 7: Frequency of Symptoms Rated Most Troubling by Persons affected by Reactive Skin Disease (%)

SYMPTOM	Awka N=60	Calab N=53	Camer N=55	Enugu N=33	Ghana N=65	Ibadan N=17	Tanza N=37	Ugand N=83
ITCHING	80.0	71.7	65.5	40.6	53.8	64.7	48.6	45.8
APPEARANCE	11.7	9.4	12.7	3.1	16.9	17.6	5.4	9.6
INSOMNIA	0.0	1.9	7.5	0.0	3.1	0.0	0.0	0.0
BACKACHE	0.0	0.0	1.8	6.3	0.0	5.9	33.3	6.0
JOINT PAIN	3.3	3.8	3.6	12.5	1.5	0.0	5.4	2.4
FATIGUE	0.0	5.7	0.0	0.0	1.5	0.0	2.7	1.2
HEADACHE	0.0	1.9	0.0	0.0	3.1	0.0	0.0	2.4
OTHERS	5.0	5.7	5.5	31.3	16.9	11.8	24.3	31.3

Table 8: Frequency of Symptoms Rated Most Troubling by Persons affected by Depigmentation (%)

SYMPTOM	Awka N=40	Calab N=33	Camer N=42	Enugu N=31	Ghana N=28	Ibadan N=49	Tanza N=15	Ugand N=15
ITCHING	45.0	51.5	57.1	12.9	46.4	36.7	33.3	40.0
APPEARANCE	2.5	9.1	4.8	0.0	25.0	14.3	6.7	0.0
INSOMNIA	2.5	0.0	2.4	0.0	0.0	0.0	0.0	0.0
BACKACHE	0.0	9.1	0.0	12.9	0.0	24.5	13.3	6.7
JOINT PAIN	30.0	15.2	4.8	25.8	0.0	4.1	6.7	20.0
FATIGUE	0.0	3.0	7.1	0.0	0.0	2.0	6.7	0.0
HEADACHE	0.0	0.0	4.8	6.5	0.0	2.0	13.3	0.0
OTHERS	20.0	6.1	16.7	38.7	7.1	16.3	13.3	33.3

The Perception of the Non-Affected

Findings from study of non-affected control subjects were similar. They were presented with a vignette and shown a photograph of CPOD and DPM sufferers with these lesions and then asked about the most troubling symptom for the individuals. They mentioned itching most often followed by the appearance of the condition. With the non-affected appearance assumes a greater importance. The table below shows that over 24% of the non-affected found the skin appearance to be most troubling. This is much higher than the 9.9% indication by the affected above. The explanation may be that the visible outward effects of an illness concern non-affected people more unless they happen to have experienced similar conditions in the past.

Table 9: Most troubling symptom according to non-affected (% of respondents)

SYMPTOM	REACTIVE SKIN		DEPIGMENTATION	
	Male	Female	Male	Female
Itching	50.7%	53.2%	33.0%	37.2%
Appearance	24.0%	25.4%	32.1%	24.0%
Can't say	6.0%	8.1%	12.8%	20.9%

The rest of the symptoms mentioned by the affected themselves pale into insignificance as less than 20% of the sample of non-affected people have mentioned them. For that reason we have not bothered to reproduce the whole table here. The perception that itching is associated with reactive conditions more than with DPM again is borne out from the responses of the non-affected. Gender does not appear again to have any effect on these perceptions except for DPM where a slightly higher percentage of non-affected women than men thought itching was a troubling problem for the affected while by a similar margin of men over women, men thought skin appearance was most troubling for the affected.

It is noteworthy that women said more often that they did not know what the most troubling aspect of the illness would be. Although persons of both sexes had said they did not have an answer, the margin is greater for depigmentation than for the reactive skin lesions. The implication may be that some respondents, particularly women, really did not think that this condition induced any obvious problems but lacked the self-confidence to make an assertion.

Associations of Onchodermatitis Symptoms

When the symptoms of onchocercal disease were studied they appeared to be linked in some cases causally. For example, certain symptoms were seen to have caused or led to certain others or in any case to be associated. These links though remarkable were not necessarily expressed by everybody and some sites seemed to have reported this more than others. A more detailed study of the data, than time would allow at the moment, using the resources available from TextBase Alpha should make it possible to explore these links further and to indicate the strength of the various associations. With this caution in mind we now quote subjects to illustrate the ways in which the causal connections were perceived by affected respondents.

ITCHING & INSOMNIA

"I have frequent itching sensation. I don't sleep well these days."

"When I scratch myself a lot, I fail to sleep at night because of the weakness. I fail to work properly"

"The itching disturbs my sleep in the night and this (insomnia) causes severe headache the next day"

"The itching affects my sleep. I have to scratch myself the whole night"

ITCHING & APPEARANCE

"It itches me and when I scratch, it develops into sores and the spots develop over them later. The black spots all over my body worry me"

"The legs itch me a lot and it has changed the skin colour"

"I have itching of the whole body and I have to scratch. When I scratch I leave scratch marks and the skin on my legs peels off to leave red spots"

"..both legs itch a lot. Whenever I scratch them fresh sores emerge"

ITCHING & FEVER

"I get severe itching all over the body. It can itch me the whole night. It also gives me a fever when itching comes"

ITCHING & PAIN

"It itches me and causes ..prick-like pains. It also causes generalised body pains and at times gives me fever"

"I scratch a lot and this results in severe pain, weakness and insomnia"

INSOMNIA AND OTHERS

"I sleep but not well due to the body pains"

"I have pains all over my body and sometimes I won't be able to sleep or go to farm"

"All my joints will just be aching and sometimes I find it hard to sleep"

Itching is mentioned more often in these links and this is because it is considered the most salient sign or symptom of onchocercal disease. Though its relationship to insomnia may be patent, respondents have nonetheless elaborated on the causal association. Although no statistical count has been taken of the number of times that respondents noticed the association nevertheless the impression that this linkage is common is strong as it is frequently met in symptom-coded text segments viewed with TextBase Alpha.

It is necessary at this point to observe that other linkages have been encountered which have not been listed here but have been included in the Onchocercal Skin Disease network developed during the study and reported elsewhere.

SYMPTOMS AND SOCIAL FUNCTIONING

Respondents who experience the onchocercal disease symptoms in question have indicated their effects on their lives. Their remarks, like the previous ones on causal links between symptoms, are spontaneous ones that should be taken for what they are worth.

Some of the symptoms were said to worry people, to embarrass them even in public, to affect sexual and marital relationships and most importantly work behaviour. Examples of such utterances are provided below as follows:

REFERENCES TO SOCIAL LIFE

"I scratch myself the whole night. I also worry a lot and think many things ; even at times I cannot eat properly"

" It has caused me a lot of embarrassment. I find it difficult to wear clothing because anytime I do that my.. skin itches and makes me feel uncomfortable"

"It itches me so much so that even in public places, I am forced to scratch my bottom and my arm"

"The itching following rashes causes me a lot of anxiety"

".. itching of my penis has taken away my strength and ability to perform sexual acts to my women"

"It affects my sexual life. I sleep with my wife and my performance is inadequate. I can only do one round"

"My mates laugh at me at school; they call me 'mother hen' (eka Unen) when I start scratching myself in the class"

REFERENCES TO WORK (ITCHING)

".. I scratch a lot when it itches and I am not able to continue with my itinerant petty trading... I also feel dizzy"

" [When] my skin starts itching very much ... I have to stop everything I am doing."

" Because of the itching I cannot work as usual; when there is sun, I cannot withstand it.."

".. the itching that takes place takes me away from my work and this worries me"

REFERENCES TO WORK (FATIGUE)

"The condition has reduced my strength and energy to perform functions like digging and walking"

"I get tired easily and this affects my work on the farm"

"I have lost strength to do my usual work like digging, collecting water, doing house chores."

"I feel tired and I have been down for some time and have not been able to do any work"

REFERENCES TO WORK (JOINT-BONE PAIN, FEVER, ETC)

"Backache is a problem too because I cannot work for long on the farm"

"I have backache that makes it difficult to work at times"

"My waist also pains severely interfering with my work.."

"I also feel feverish in the evenings and morning which means that I cannot go to dig before 8.00 am, and I must be back by the fire side in the evenings"

COPING STRATEGIES

From the open-ended questions that generated the responses on symptoms we also noticed some respondents talking about the ways in which they coped with their onchocercal disease problems. These coping strategies can be paraphrased in the form of DOs and DON'Ts as we have done below.

The schedule's questions on help seeking behaviours and treatments came later in the course of the interviews but since respondents themselves have volunteered at this early point to discuss the ways in which they dealt with their problems personally we deem it essential to include their remarks here especially as they refer to the symptoms of the disease rather than the entire onchocercal condition. We must remark however that these comments were provided mostly by reactive skin disease cases.

USE STONE

"I get generalised body itching and I have to scratch myself sometimes with a stone. If I bathe "

STONE AND HOT WATER

"I get generalised body itching and when it is intense I have to scratch myself with a stone and (...) hot water. After scratching myself I get blisters and a burning sensation."

OIL

I have problems around my anus and buttocks. The whole place has wounds and skin lesions that itch a lot and cause me to scratch. It gives me problems when I go to toilet. The place needs to be oiled or it cracks painfully"

GIN & CORN DOUGH

To soothe it (i.e. the itch), I would mix corn dough and akpeteshie (local gin) and apply to the affected area. I feel a little relief when I apply this..

DRINK LOCAL GIN

I had to take in large quantities of local gin "Akpeteshie" before I would get some relief.

BUY AMPICILLIN FROM DRUG STORE

It itches me sometimes and .. I go to the local drug store to buy ampicillin which reduces the itching a bit

DON'T WEAR CLOTHING

I find it difficult to wear clothing because.. my skin itches and I feel very uneasy.

DON'T EAT MEAT

"The itching is worse when I eat meat, so now I do not eat meat"

DON'T HAVE COLD BATH

"I get generalised body itching mainly in the rainy season and when it is cold. After bathing with cold water I get the same problem".

DON'T WALK IN THE SUN

"Any time I walk in the sun and later go home I will scratch my body all the time"

CONCLUSIONS

1. Itching is seen by both oncho-affected and non-affected individuals as the most common symptom of onchocercal skin disease. We note however that affected individuals do not distinguish the source of itching according to biomedical categories of disease.
2. Appearance is a concern reported more frequently by the non-affected persons than by the affected.
3. Concern about itching in depigmentation is site-specific, more an issue in some sites than in others, where it is not considered troubling.
4. Onchocercal symptoms are particular coping strategies, which affected individuals may devise for themselves.
5. Affected individuals show concern that symptoms impair their ability to work, interact socially, and affect other facets of their lives.

STIGMA ASSOCIATED WITH ONCHOCERCAL SKIN LESIONS

The present study was conducted to determine the nature of psychosocial impact of onchocercal skin disease in oncho-endemic communities. It was hoped that the findings would provide insight into the extent and nature of psychological, social and personal suffering resulting from onchocerciasis. This section focuses on the issue of stigma associated with various skin lesions in onchocerciasis.

METHODS OF STUDY

Information on stigmatisation was obtained using a combination of methods; namely: pre-coded and pre-structured questionnaires, focus group interviews, in-depth interviews, and participant observations. Semi-structured interviews addressed the following agenda:

- * Personal identification.
- * Demographic characteristics.
- * Patterns of disease-related distress: symptoms, name of condition, meaning of name of condition, personal feelings about illness, impact of illness on the person, onset and duration of illness.
- * Perceived causes of condition.
- * Help-seeking history and preferences.
- * Suggestions for prevention of condition.

Interview items to elicit participants' experiences of onchocercal skin disease. Numerical data were analysed using EPI INFO software and qualitative materials were analysed with the help of TextBase Alpha.

The study involved two groups of interviewees: individuals who suffered from onchocerciasis, and a control group of persons who were free of infection with *O. volvulus*, as demonstrated by absence of subcutaneous nodules and microfilaria in skin snip from both iliac crests. The control group included one sub-group living in the same communities from which affected persons lived, and the second sub-group came from an area considered to be relatively free of onchocerciasis. The rationale for studying the three groups was to determine probable differences between them on issues of stigma. (See appendix 1).

A scale was constructed around ten indicators of stigma, including disclosure, esteem, leadership, heterosexual relationships, pity, avoidance, shame, marriage and sexual functioning. Stigma based on each of these themes was assessed using questions framed about each theme. A question elicited either a "Yes", "Possibly", "Uncertain", or "No" response. A "Yes" answer was scored 3; "Possibly", 2; "Uncertain", 1; and "No", 0. (See appendix 2).

A stigma score for each individual was computed by summing up the numerical values for all the responses for the person concerned. The means of stigma scores for all study subjects at each site were calculated and correlation coefficients between stigma scores and disease type, sex, age, education type and region computed. Experience with study subjects suggest that a mean score of 6 or more on the stigma scale indicates a significant level of stigma associated with onchocercal skin disease.

RESULTS

For reactive skin disease (RSD) at seven out of eight sites, 30% or more, of affected subjects reported low self-esteem because of their skin conditions. At least 33% of affected subjects said they would find it difficult to marry as a result of their skin condition. Depigmentation (DPM) elicited somewhat less of these concerns than RSD. The level of stigmatisation increased with the level of education of study subjects. Control subjects who did not suffer from onchocercal skin disease reported higher levels of stigma associated with the disease than affected persons (Table 1).

Table 1: Mean Stigma Scores for Reactive Skin Disease and Depigmentation among Affected and Control Subjects

Lesion	Affected	Unaffected
Reactive Skin Disease	11.8	22.5
Depigmentation	9.0	19.3

Indicators of stigma referred to many aspects of the lives of individuals including personal, social, psychological, and economic effects. Some affected persons think less of themselves or think they are worthless, and 1-2% consider suicide. Onchocercal skin disease limits the range of social involvement of affected persons. Individuals feel ashamed of themselves, worry a lot over their skin condition, fear that the disease might kill them, and experience low morale. In addition, affected persons feel socially up-rooted from their communities.

Qualitative analysis of the prose accounts of individuals indicated that the nature of human responses to the problem of onchocercal skin disease is complex. While society feels sorry for, and pities those who suffer from the condition, they also avoid, despise, and make fun of the sick. The following excerpt from a focus group discussion illustrates this point.

"People think less of them and their families. They are ignored and silenced and even despised. Their women, children - all are despised.... People use their skin condition to insult them or their family. Look at them, your father's skin looks like that of a lizard or your husband's"

Affected people are stereotyped as weak, emotionally dull and cold, and as unable to perform their duties, let alone, feed themselves. They are considered dangerous and dirty, and they are avoided for fear that they might pass on their disease to others. People would not elect them to positions of leadership, and oncho-affected individuals said they think less of themselves, suffer lack self-confidence, and might embarrass the people they would represent. ("How can you stand before people with a skin like that?").

The person who suffers from onchocercal skin disease may be compared with an animal because of his or her skin, and behavior. Individuals were likened to a lizard, a monkey, a vulture, and mother hen. The individual is considered mannerless and his or her behavior distracting, interfering and embarrassing for others. The dignity of the oncho-affected person is thus severely compromised.

Although most individuals with onchocercal skin lesions said that their family members who were not affected with onchodermatitis would have no problems marrying, most of non-affected control subjects say they would.

The following quotations from interviews illustrate what oncho-affected persons and non-affected people had to say about the issues related to stigma.

Esteem: Non-affected Persons

He will even feel like committing suicide.

Life will not be worth living again. People will always turn around to take a second look at him.

She will not be able to attend a lot of social functions and so the depression will cause her to think less of herself.

The person will always be ashamed of himself.

He will feel that he does not belong to the society anymore....

Her spirit will always be low, that is , it will affect her morale.

They won't respect her because she is not whole again.....

Esteem: Affected Persons

It itches me and makes my skin look bad and makes people resent me and makes me feel useless.

They would think less of me. Even my own children tease me; they call me "monnu" - meaning whiteman. Young kids laugh at me. So I hide it most of the time. I do not want people to know about it.

You feel my body to find out what gwenyu does to the body - rough. I feel useless.

Yes, I am ashamed of the appearance of my skin.

I am failing to look after my health. I am struggling to get treatment for myself. I need to survive and get money to live on. The disease is interfering with my plans to live.

DISCUSSION ON STIGMA

Quantification of stigma in onchocerciasis makes it easier to specify and compare an important aspect of the burden. An examination of mean stigma scores for various study sites showed that there were differences that could be explained by cultural context. At Awka, Nigeria, DPM is regarded as a sign of wealth and ageing. At Calabar, Nigeria, DPM is associated with beauty and therefore not stigmatised. The mean stigma scores at these two study sites were therefore low for DPM.

Oncho-affected indicated stigma was less than did non-affected interviewees. Several explanations could explain this. Affected persons reported that they were not responsible for their skin afflictions; that it was God who sent the condition to them, possibly to test them. Also, as psychological defense mechanisms to cope with stigma, denial, suppression, resignation and rationalisation may make stigma easier to bear. ("This condition is always with me. There is no point feeling embarrassed about it." "Nobody avoids me; God will not make me an epileptic person".) On the other hand, for non-affected persons it is easier to cope by distancing themselves from the condition, and hence stigmatizing it. On the whole this study has shown that onchocercal skin disease is associated with significant levels of stigmatisation for affected people and their families.

CONCLUSIONS FOR STIGMA

- Onchocercal skin diseases are associated with severe stigmatisation. Both reactive skin disease (RSD) and depigmentation (DPM) are stigmatized, RSD more so than DPM. The social meanings of DPM are site specific, and in some areas desirable.
- Subjects with more education have higher stigma scores for both RSD and DPM.
- Males have higher stigma scores than females for RSD and DPM.
- With increasing age stigma decreases, more so for DPM. This effect is most prominent for women with DPM.
- Oncho-affected persons report less concern about issues related to stigma than non-affected persons in the community. Control villages did not differ from oncho-affected villages with respect to levels of stigma reported by non-affected persons.
- An assessment of stigma with methods used in this study may provide a useful indicator of the burden of onchocercal skin diseases and the need for control programs. Stigma and other findings from the study show that suffering arising from non-blinding onchocerciasis also requires efforts of control programmes.

HELP SEEKING AND COPING MECHANISMS

Introduction

What do people do to cope with onchocercal skin lesions ? Where do they go for help ?

In order to address these questions the last part of the psychosocial report will cover four main areas namely:

- 1) Do people in the study communities perceive onchocerciasis as a serious matter of concern to them ?
- 2) Do people perceive the condition as treatable ?
- 3) What kinds of treatments do they currently use and where do they get them ?
- 4) How much is onchocerciasis a financial burden on affected people and their families ?

Methods

In order to address these issues there were eight questions in the semi- structured in interviews (questionnaire) which were posed to each respondent. These questions were:

- Q.1 Is your condition a serious matter of concern?
- Q.2 Do you think any treatment would be effective for your condition?
- Q.3 Is yours the kind of condition that the white man's doctors or traditional healers can help with?
- Q.4 What have you done for yourself to deal with this condition?
- Q.5 What kinds of help have you made use of for your condition?
- Q.6 Among all the sources of help you consulted ... which one of them do you consider the most important?
- Q.7 How is it you consider this one the most important?
- Q.8 Was it a strain on your or your family's finances to pay this much money?

Results

Table 11 below summarises the result whether people in the affected communities perceive the onchocerciasis as a problem:

Table 11: Subjects perceived seriousness of onchocercal skin disease (% of respondents)

Seriousness	Reactive Skin Lesion (RSD)	Depigmentation (DPM)	Total
Not serious	14.2	27.0	19.0
Moderately Serious	30.1	19.1	26.0
Very Serious	52.6	50.9	52.0
Uncertain	3.1	3.0	3.1

The results in this table suggest that 8 out of every 10 people interviewed perceive onchocerciasis as a serious matter of concern to them. About half reported it was a "very serious" matter. Prose conveniently indicates the nature of these concerns, for example,

"It is a serious matter of concern because it may make me unable to walk and to work" (Ghana).

There is hope among the people who took part in this study that there is cure for them (table 12 below). A very small proportion (5.3%) however, did not believe that there is a cure, more among those with depigmentation. The following two quotes from Ghana and Enugu elaborates this idea more clearly

"I feel that if I am sent to hospital I will be well again" (Enugu, Nigeria)

" With treatment the areas with the condition will be just as my normal skin. Without treatment it will spread and cover all my legs" (Ghana)

Table 12: Opinion of respondents with reactive skin lesions and DPM about effectiveness of treatment for their condition (% of respondents)

Perceived effectiveness	Reactive Skin Lesion (RSD)	Depigmentation (DPM)	Total
Yes	72.2	57	66.5
Possibly	10.5	12.6	11.3
Uncertain	12.8	23.7	16.9
No	4.5	6.7	5.3
Respondents	446	270	716

When asked about what types of medical system they expect will be effective (table 13), responses clearly favour modern medicine over traditional healers. Nine out of every 10 people in this study said that modern medicine is more effective for both reactive skin lesions and non reactive skin lesions with no significant differences across the sites. There was only one site (Awka) where people did not show very strong trust in modern medicine in treating depigmentation. Qualitative data, however, suggest this may be an artifact of cultural beliefs in that depigmentation is a normal aspect of ageing.

"I think the itching can best be treated by modern medicine. Because all the herbs have failed. When I got tablets I got relief for a while. So it is tablets that can best treat this problem" (Uganda)

"If I had money I would go to hospital. This is because it is the only place that I think can treat this problem" (Ibadan, Nigeria)

Table 13: Subjects perception of the effectiveness of modern medical and traditional treatment (% of respondents)

Treatment Type	RSD	DPM	Total
Modern Medical: Yes/Possibly	93.1	84.7	90
Traditional Healer	27.8	25.4	26

Table 13a: Subjects perception of the effectiveness of Modern Medical treatment by site (% of respondents)

Type of Lesion	Awka	Cameroon	Calabar	Enugu	Ghana	Ibadan	Tanzania	Uganda
RSD	96.7	90.7	89.4	94.4	92.3	100	93.1	92.9
DPM	60	81	88.5	90.6	92.9	94.2	92.3	80
TOTAL	82	86.5	89	92.6	92.5	95.8	92.9	90.9

Table 13b: Subjects perception of the effectiveness of Traditional treatment by site (% of respondents)

Type of Lesion	Awka	Cameroon	Calabar	Enugu	Ghana	Ibadan	Tanzania	Uganda
RSD	35	18.5	60	90	9.2	33.3	18.8	28.6
DPM	0	19	75	75	7.1	35.3	19.2	28.6
TOTAL	21	18.8	64.7	81.8	8.6	34.8	18.9	28.6

Most people try some kind of home remedy. It seems from the prose accounts that the current primary health care system does not have medicine to treat onchocercal skin lesions. The lack of drugs in hospitals, dispensaries and even local retail shops frustrates the patients and they must rely on home care and help from friends.

"I have been going to hospital, but they don't have medicine. Probably if they had given me medicine, I would have recovered". (Tanzania)

"I have bought some tiny tablets and used them to treat this condition. I found them to have been very helpful, but I can't get any to buy now. The tablet in question is called Letogen." (Ghana)

Table 14 still suggests that modern medicine is people's second choice after self-care. The proportion of those who said they don't use any service is also worth noting. The fact that nearly

26 % of patients with depigmentation do not seek any care may be a result of hopelessness.

Table 14: Types of help used by respondents

Types of help	RSD %	DPM %	Total %
1. Self Care	53.8	46.7	51.1
2. Help at Home	31.7	33.1	32.2
3. Friends/Relatives Outside	18.4	18.1	18.3
4. Chemist/Pharmacy	36.7	31	34.5
5. Modern Doctor/Hospital	42.7	39.7	41.6
6. Traditional Healer	25.3	27.5	26.1
7. Faith healer/Pray house	8.1	13.3	10
8. Other	2.5	26.8	22.6
9. *None (142 Cases)	20.1	26.8	22.6

*None: Individual respondents who have not mentioned any type of care

People in these communities may use a combination of treatments and services. People from different sites cope in various ways.

"I add palm kernel oil to penicillin powder and apply to the affected place. I have also had injection from a community clinic attendant." (Ghana)

"Yes, I have gone to both traditional and modern medicine ..." (Uganda)

"At first I did not believe it to be a very serious condition, but later ... I decided to consult a diviner, over there I was not satisfied, so my husband then took me to the hospital." (Female, CPOD, Ghana)

"I have helped myself by buying local soaps and medicine. Also I went to hospital and traditional healers." (Awka)

"I believe that help from God and doctors are the important ones. The doctors are the ones God will use to help me; God is the greatest doctor." (Ibadan)

"It is more reliable to trust in God rather than oracles that deceive people." (Enugu)

Among all the sources they had used, respondents were asked to identify those that were most important. Table 15 summarises these results across all the sites. Less than half of those interviewed said modern doctor and hospital is the most important source of help. Despite the value attached to modern medical services, cost is a barrier.

"I believe that modern doctor will be the most important because traditional herbs have not improved my condition. It (modern medicine) is quicker, reliable and easier. Although, it may be costly but good health is needed" (Ibadan, Nigeria)

"Though I have not yet improved, I believe medical doctor is still the best. That is why I came here today. Itching at least stops after taking medicine" (Uganda)

Table 15: Most important source of help (% of respondents)

Type of help	RSD n=429	DPM n=266	Total n=695
Chemist/Pharmacy	12.4	10.9	11.8
Modern Doctor/ Hospital	42.2	38.0	40.6
Traditional healer	2.8	4.1	3.3
Faith healer	2.6	3.8	3.0
Other	2.3	0.4	1.6
Divine oracle	0.0	0.8	0.3
None	25.4	33.1	28.3
Can't say	12.4	9.0	11.1

Although more specific information would be useful, it appears the condition imposes the condition imposes considerable financial burden on the affected. Four out of 10 people interviewed said they experience financial strain from the condition. The economic burden also includes the reduced productivity resulting from the disease as well as the cost of services, treatments and time spent obtaining medical services.

"I use energy to go to hospital... I can not tell you how much it costs me" (Tanzania)

" I have spent 20,000 cedis on it...it was a strain on me" (Ghana)

Table 16: Subjects perception of the financial burden of onchocercal skin disease on individual and family resources

Financial Burden	RSD (%)	DPM (%)	Total (%)
Nothing spent	23.6	35.6	28
No strain	22.7	15.4	20
Some strains	19.9	15.8	18.4
Considerable strain	21.1	16.6	19.4
Cannot specify	6.9	9.5	7.8
Cost unknown	5.9	7.1	6.4

So far we have been referring to the questions we asked our subjects. The data which formed the basis of discussion consists of frequencies in response to several questions about help seeking and ways of getting help for people's onchocercal skin diseases. In order to make comparison across sites, however, we find it useful to summarise the from several of these variables in a summary variable that was computed. This summary variable accounts for variations in the priority attached to help-seeking sources, as indicated by responses to the following questions:

- i) Open ended question about sources of help the subject have used.
- ii) Perceived usefulness of those health care providers that have been used.
- iii) Health care provider used first.
- iv) Health care provider identified as most important.

A score for each source was computed based on relative weights associated with some of these queries (i.e., most important [5], first help sought [3], usefulness [3], and emphasis [4]. To compare self-care and home remedies, scoring excluded contributions from "most important" and "first" help sought. Table 17 summarises the mean score for all types sources of help used in the study villages across all the sites. It is clear from the table that there is consistency in the pattern of use of various sources of care across the study sites. The mean scores still indicate that help at home and friends and relatives lead, followed by modern doctor and hospital. These scores make it easier to compare help-seeking sources across sites.

*Table 17: Mean Scores for All Types of Sources of Help Used in the Study Villages:
(Not including "Most Important" and "First Help Sought")*

SOURCES OF HELP	RSD	DPM	TOTAL
HELP AT HOME	2.06	1.97	2.01
FRIENDS AND RELATIVES	1.26	1.35	1.28
CHEMIST AND PHARMACY	0.74	0.73	0.73
MODERN DOCTOR/HOSPITAL	1.66	1.63	1.64
TRADITIONAL HEALERS	0.78	0.83	0.8
FAITH HEALERS	0.32	0.47	0.37
DIVINER/ORACLE	0.07	0.17	0.11
OTHER	0.12	0.13	0.12

Conclusions

Following from these results one can make the following conclusions:

- Onchocercal skin diseases are said to be serious, either moderately or very serious, in the sites we studied by nearly 4 out of 5 people affected.

- Within these communities, despite the chronicity of these diseases, 9 out of 10 people have hope that modern medical treatment can help them. Also, 1 in 4 people believe that traditional medicine can be helpful.
- We find that from what some people have told us, they are disappointed by the unavailability of medicine at the clinics available to them. This may explain in part why fewer use modern health care facilities compared to the number who say such facilities would be useful.
- Almost 2 in 5 patients experience at least some financial strain resulting from their skin condition. They tell us that the illness also reduces their productivity.
- Computing a summary score to account for prior experience with various health care providers, we have demonstrated the significance of modern medicine and identified some variation across sites, which is the subject of our ongoing analysis.

MAIN CONCLUSIONS

Onchocercal skin disease is an important public health problem in the affected communities studied. Over 30% of the population in the endemic communities had onchocercal skin lesions. The most prevalent among them are chronic papular onchodermatitis (affecting 13.1% of the population), acute papular onchodermatitis (7%), and depigmentation (9.5%). They impose a burden of severe itching and other symptoms that have important personal and psychosocial effects not only on the affected individuals, but also on their families and communities.

ENDEMICITY

There exists a strong correlation between the burden of onchocercal skin disease and the level of onchocerciasis infection in the community.

SYMPTOMS

- For the affected people, the most serious consequence of onchocercal skin disease is itching, which is often very severe, and according to those affected the cause of sleeplessness, fatigue and weakness. More than half of the population of hyper-endemic populations is suffering from troublesome itching as a result of onchocerciasis.
- Troublesome itching leads to scratching, often with stones, twigs or knives, and results in bleeding wounds, sores and pain in the affected parts of the body.

PSYCHOLOGICAL AND SOCIAL IMPACT

- Symptoms make it difficult for onchocerciasis-affected persons to concentrate, work and interact socially.
- Such persons may also suffer from poor self-esteem and become socially ostracized as a result of illness-related stigma.

CORRELATES OF ITCHING

- Clinical evidence indicates that troublesome itching is related to reactive onchodermatitis and findings from the psycho-social component of the study suggest that itching may also be associated with depigmentation.
- Non onchocercal skin disease contributed very little to troublesome itching in the affected communities.
- The prevalence of troublesome itching showed a strong correlation with the level of endemicity of the community ($r=0.75$, $p<0.001$). Extrapolating from this relationship, it is estimated that more than 8 million people in Africa are suffering from troublesome itching as a result of onchocerciasis.

REACTIVE SKIN DISEASE

Reactive onchocercal skin disease (RSD) affected approximately 20% (range 10%-70%) of the population of affected communities.

- RSD was an important cause of stigma in most endemic communities, and affected people's self-esteem and self-respect.
- Affected persons often refused to disclose their condition because they felt they would be embarrassed or avoided by others. They also felt that disclosing their condition may affect their chances of getting married, and that RSD affected their chances of being elected to leadership positions.
- Most felt that RSD could best be treated by the doctor in the hospital.
- The prevalence of reactive skin disease showed a statistically significant relationship with the level of endemicity of the community.

ONCHOCERCAL DEPIGMENTATION

- Onchocercal depigmentation was very frequent in the elderly. Concern about onchocercal depigmentation varied across sites and among individuals, troubling in some areas, but not in others.
- There was a significant difference between the prevalence of onchocercal depigmentation in East and West Africa. Prevalence of onchocercal depigmentation, especially Leopard Skin, was very prevalent in West Africa but rare in East Africa, even in highly endemic areas.

RECOMMENDATIONS

Given the heavy burden of onchocercal skin disease,

- There is an urgent need to establish onchocerciasis control in the many endemic communities which have a significant burden of onchocercal skin disease but which have previously received low attention because of absence of or low prevalence of onchocercal blindness.
- In view of the high correlation between the severity of skin disease and the level of endemicity as measured by the prevalence of palpable nodules, we recommend that nodular prevalence be routinely used to estimate the burden of onchocercal skin disease.
- There is need for further studies to explain observed variations in the epidemiology and psychosocial impact of the disease in various study sites. For example, the East/West variation in the disease pattern could be due to parasite/host factors, and DNA probes should be used to investigate possible differences in parasite strains between these two regions of Africa.
- More detailed studies to determine the economic impact of non-blinding onchocerciasis are needed.