

**HELP SEEKING BEHAVIOR AND COPING
WITH ONCHOCERCAL SKIN DISEASE
IN ENDEMIC COMMUNITIES OF SOUTHWESTERN GHANA***

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COPING WITH ONCHOCERCAL SKIN DISEASE IN ENDEMIC COMMUNITIES OF SOUTHWESTERN GHANA**

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Abstract:

Onchocercal skin disease triggers its own peculiar help-seeking and coping strategies which need to be studied in their own right and against the background of the poor rural communities where it is endemic. While conditions like blindness excite the sympathies of urbanite decision makers who control budgets and healthcare resources, onchocercal skin disease remains for some a nebulous ailment lacking significance as a health issue. In this context, rural communities devise a variety of organised and informal or unorganised help-seeking modes and sundry coping behaviours that include the negative, the passive and the positive in their search for meaning and relief to a condition which the policymaker is unlikely to ever experience.

Key words: onchocercal skin disease, acute papular onchodermatitis, chronic papular onchodermatitis, lichenified onchodermatitis, depigmentation, help-seeking, causes, Ivermectin, coping strategies

Introduction:

The Webster Third New International Dictionary of English defines coping as to maintain a contest or combat usually on even terms or with success; to face or encounter and find necessary expedients to overcome problems and difficulties. Coping, from the psychological point of view, makes an irksome condition tolerable. The suffering due to onchocercal skin disease, indeed any ailment, is seen as a problem that impinges on life adversely and triggers responses aimed at mitigating the suffering. The affected people show by their behaviour, comments and attitudes that they cope with onchocercal skin disease in various ways. These ways can however be categorised roughly into negative, passive and positive strategies. No value judgements are necessarily attached to these adjectives in this account.

Background Information

Onchocerciasis is a disease attributable to *Onchocerca volvulus*, a parasitic filarial worm of the family of dipetalonematidae. It affects many on the African continent, with social, economic, psychological and other health repercussions. Mudoch et al (1993:260) remark on its prevalence throughout tropical Africa. They refer to WHO estimates that worldwide, 80 million are at risk while 17.8 million are infected. Recent WHO estimates of those at risk now suggests 126 million. The disease burden due to onchocerciasis, as estimated by WHO in 1990 was 884,000 Disability Adjusted Life Years (DALYs) of which itching alone accounts for over half.

The known vector for the disease is the black fly (*Simulium Damnosum*), a fly readily recognised in southern Ghanaian endemic communities and known as **ntummoa**, meaning “black insect or fly” in Akan languages and **nkontea**, in Brussa. Its bite is described by respondents as painful and causing instant itching. Species of *S. damnosum* can be found in forest or savannah ecologies where it is known to lay its eggs on rocky outcrops in fast flowing rivers where its larvae benefit from the oxygen in water bubbles and are able to pupate and develop into adult flies.

Flies may or may not be infected. The infected fly through its bite transmits to humans or even livestock microfilariae. These may grow into the adult (macro)worms that live in subcutaneous nodules in the body of affected. The female adult worm produces millions of microfilariae (mf) found under the skin of an infected person and their migration and dying in large numbers cause toxic reactions which manifest in skin lesions, blindness, itching and general health problems. Collins et al (1995) citing evidence from Duke (1975) report that factors that determine severity of the disease and prevalence in endemic communities include among other things the proportion of infected flies, the number of infected larvae per fly, and the biting rate.

Treatment of the disease in the past has employed chemotherapy and other measures including nodulectomy (removal of nodules). Ivermectin, (Mectizan) has been the treatment of choice since 1987 when Merck donated the drug free for treatment of endemic communities. Ivermectin kills the microfilariae but not adult worms. Its side effects are mild in comparison with alternatives. However it is expected that since the adult worm remains in the body for about 12 years, by treating affected communities en masse for a sufficiently long period the transmission cycle would be interrupted leading to the containment of the disease. Other drugs used in the past included **Diethylcarbamazine** (DEC), or banocide, a microfilaricide with dangerous side effects which did not make it suitable for mass treatment regimes. **Suramin**, used in the treatment of sleeping sickness since the 1920s, was also used to treat onchocercal disease.

Attempts at controlling the disease in West Africa began in the 1970s with the setting up of the Onchocerciasis Control Programme of West Africa. (OCP). The activities of this agency have

included

annual treatment of endemic communities en masse with Ivermectin, larvaciding, involving periodic aerial spray of river stretches and scientific research on the disease in an attempt to break the transmission cycle of the disease. These activities have done on in several countries mainly in the savannah zones where the blinding aspects of the disease have been prevalent. The northern parts of Ghana drained by the tributaries of the Volta have benefited from these activities which have been responsible for the reduction of the burden of the disease in communities lying near the banks of rivers.

Regrettably, the Onchocerciasis Control Zone of OCP did not extend to the rest of Ghana lying south of latitude 7° 30' N and to the Southwest side of the Kwahu Plateau, the major watershed that separates the Volta basin from the Southwestern river basins. Efforts by the Ghana Ministry of Health with the collaboration of some NGOs has not been effective in controlling the disease in the endemic communities in Southern Ghana. Not only is treatment haphazard in those communities earmarked for mass treatment, many other endemic communities have yet to be treated.

This paper discusses the findings of several studies conducted between 1993 and 1997 in some of the endemic communities of southern Ghana on the dermatological aspects of onchocerciasis. The paper attempts to present and discuss findings on coping strategies of Ghanaian peoples in those rural communities for which the skin disease and its perceived symptoms, especially itching, were studied.

A 56 year old with DPGM comments as follows: “Years ago I bought gun powder which I sprinkled on the affected part and applied matches to it. The flames came but after several attempts without effect I had to discontinue this. I thought some small 'insects' were causing it but the treatment did not work.” Remarks such as these show the extent to which onchocercal skin disease and its symptoms can be a bother to affected people and involve them in unorthodox, if not dangerous behaviours.

Onchocerciasis is generally equated with blindness, hence the term "River Blindness". Nevertheless, blindness is not its only or main sign or symptom nor are all manifestations of blindness, even in endemic communities, due necessarily to onchocerciasis. The disease has also been known to cause certain kinds of dermatitis including reactive skin lesions, nodules, hanging groins, skin atrophy,

itching etc. Some researchers in Nigeria, (see Pearson, 1985, Pearson et al 1985) and Malawi, (see Burnham 1991), have associated it with musculo-skeletal pains. To these can be added chronic debilitation, reduced immune responses, and increased adult and child mortality, see Hunter (1981: p 261), elephantiasis of the genitals and weight loss, Samba (1994:5), Buck (1972:15). Kipp et al (1993) and Ovuga et al (1992) have observed an association between prevalence of epilepsy and onchocerciasis in Uganda which Kaiser et al (1996) have corroborated in another study. This association of onchocerciasis and epilepsy has been suspected for sometime, see WHO Expert Committee on Onchocerciasis Third Report 1987.

Onchocercal Skin Diseases (OSD) of particular interest in this paper include the following: Papular Rashes: Acute Papular Onchodermatitis (APOD): small (1-3 mm diameter), widely scattered papules with vesicles, and pustules in more severe cases. Favourite sites are the limbs, trunk and faceⁱ. Chronic Papular Onchodermatitis (CPOD) manifests as flat-topped papules (3-9 mm) usually found on the buttocks, waist, shoulders. Lichenified Onchodermatitis (LOD), popularly known as “lizard skin” and *sawda*, in Yemen consists of abnormal patches of skin or plaques, pigmented, rough to the touch and darkened. Favourite sites for it are one or both legs, but could affect other parts of the body too. Depigmentation (DPGM): “leopard skin”, as it is popularly known, is in the form of patches of complete pigment loss with islands or spots of normally pigmented skin centred around hair follicles. Favoured areas are the shins, but occasionally groin and lower abdomen are affected. All of these conditions may be associated with itching which is the symptom most feared by affected respondents. Non-affected respondents seem to be equally concerned by the outward appearance of the lesions.

An elicitation of local terms for onchocercal skin lesions yielded numerous items the most salient of which are **epini** and **nzooso** for LOD, **sabeng koko** or **kokole** in Brussa language for DPGM and **akele** and **asee** for APOD and CPOD.

ⁱ The classification is based on Murdoch et al (1993).

Methodology:

Data was collected in three different studies: the Skin disease study which investigated the importance of onchocercal skin disease, part of a WHO multi-country study, the Ivermectin study which investigated the effect of Ivermectin on onchocercal skin disease and itching and a Socio-demography study which was interested in the potential effect of population movement in the recrudescence of onchocerciasis in the Lower Black Volta zone which falls within the purview of OCP.ⁱⁱ

Two semi-structured interview guides for affected and non-affected respectively were employed. Interviews with the non-affected were facilitated by the use of photographs depicting CPOD and DPGM lesions accompanied by a vignette. The Ivermectin study lasted over a year (August 1995 to November 1996) during which six study visits were made. All respondents were examined on each occasion for onchocercal skin lesions which were then photographed. On all visits interviews and treatment were administered, although in this trial study employing Ivermectin and placebo, the researchers were blind as to which of these was given to particular respondents^{iii iv}.

Questions on help-seeking included among others, causes mentioned with or without probing, decision on most important cause, perceived modes of help-seeking past and present, and responses to probes on specific causes, assessment of the importance of help-seeking in the past, reasons for choices, satisfaction with help-seeking, family support and costs of help-seeking modes.

ⁱⁱ This writer was one of the social science investigators for the WHO/TDR Multi-country studies and was responsible for the social aspects of the investigations in the Ghanaian sites. In the case of the Demographic survey, the writer was the sole investigator hired by OCP to conduct that study.

ⁱⁱⁱ At the baseline and the final visits affected respondents were administered a more detailed questionnaire on the effect of their lesions on life.

^{iv} The advantages of semi-structured interviews are that they enable the collection of both quantitative and qualitative data. Counting “yeses” and “nos” in structured questionnaires generate statistics; unfortunately, not all “yeses” are equivalent. A “yes” may sometimes be something other than a yes. Texts however enable us to appreciate the value of yeses and nos in their context. The researcher often does not even know all the relevant questions to ask and the use of qualitative methods assume this, as Heggenhougen (1991) suggested.

Sampling Communities:

Individuals and communities were selected and categorised for research purposed on the basis of nodule palpation and physical examination. 3 Hyper-endemic and 1 Hypo-endemic communities selected from within ten miles radius of the Aowin-Suaman District capital of Enchi participated in the Skin study. In the case of the Ivermectin Study all 4 communities were hyper-endemic and located further off from Enchi^v. For the demographic study most of the Southwest river basin communities were hyper-endemic with the exception of one hypo-endemic village and a few meso-endemic communities.

Sampling of Individuals:

Skin Study included 94 affected and 116 non-affected aged over 19 years with at least 5 years of residence in the study area. For the Ivermectin Study there were 1010 affected and non-affected, aged over 16 years and at least 5 years of residence in study area. The Demographic Survey registered 1008 from the Lower Black Volta zone and the Southwestern river basins. Neither nodule palpation nor physical examination had been carried out for this sample although OCP had previously paid short study and treatment visits there. Respondents were aged 20 years and over some of whom were new migrants.

General Patterns of Help-seeking Exemplified by some Sites:

To answer the question, to what extent onchocercal skin disease impacts on help-seeking, we need to know what the help-seeking options are in communities and what types are generally favoured. Table 1 provides data from the baseline study of communities in which the Ivermectin study was conducted.

Table 1: Types of Help-Seeking: Ivermectin Sample

	Spontaneous Mention		Probed Responses^{vi}	
HELP-SEEKING	(N=996)		(N=997)	
Self-help ^{vii} :	453	45.5%	499	49.9%

^v People at Enchi, the District capital, referred jokingly to the towns of Jema and Assemkrom as “Overseas”, due to their remoteness.

^{vi} Probed responses result from respondents being asked if they have utilised a suggested help-seeking mode. They might affirm, affirm with emphasis or deny the suggestion. In the case of spontaneously mentioned responses no suggestions were made to the respondent. The latter set of responses are therefore given more weight.

^{vii} Self-help includes use of local recipes, herbs, enemas, ointments and some pharmaceuticals. The latter might be borrowed from others, or they might be old medications acquired for some other

Chemist-Drugstore:	492	49.4%	655	65.7%
Hospital:	175	17.6%	237	23.8%
Traditional Healer:	30	3.0%	135	13.5%
Others	10	1.0%	29	2.9%

The local drugstores are mentioned most frequently as facilities where respondents go for help when they are unwell. Next in importance is self-help which exploits local knowledge of treatment, using local and non-local materials. In addition to the open ended question respondents were asked if they had used specified modes of help-seeking. The result is that the use of self-help jumped by 5% points, Hospital by 6% while use of drugstore and traditional healers jumped by 16% and 10 % points respectively.

Table 2: Most Frequently Used Mode of Help-Seeking:
According to Ivermectin Sample

MOST USED	Freq	Percent
Self-help	234	23.6%
Chemist-Drugstore	503	50.7%
Hospital	100	10.1%
Traditional Healer	35	3.5%
Others	12	1.2%
None	108	10.9%
Total	992	100.0%

It is undeniable that these communities relied more on the drug store than on any other help-seeking mode. The favourite drugs were painkillers and sedatives including “paracetamol” also referred to as “para” and Indocin (Indomethecin MSD), known locally as “Akakorabebobol” [lit. ‘the old one can now play football’]. These are rarely used specifically to treat onchocercal skin conditions or their symptoms. The biomedical facility runs a distant third while the interest in the traditional healer is apparently negligible.

Table 3: Reason for Importance of a Help-Seeking Mode
Ivermectin Sample (N=880; multiple mentions permitted)

	Freq	PCT
Experience	401	45.6%
Financial Cost	293	33.3%
Accessibility	251	28.5%
Reputation	80	9.1%
Referral	21	2.4%
Spiritual power	15	1.7%
Others	28	3.2%
Uncertain	10	1.1%

condition.

Reasons for the choices these rural people tended to make range from experience with a particular type of help-seeking to the issue of cost and proximity. Financial and proximity reasons explain why hospitals would not be used frequently because there were none in the immediate vicinity of the villages in question at the time of the research. Moreover, hospitals charge fees for their services, not to mention transportation costs which add to the financial burden of the ill. Coleman (1997) illustrates how district level health care services might, in the Ghanaian context, cost the user more than the charges at the Regional hospitals.

To understand why local people might or might not seek treatment for their skin lesions, we needed to know more about their perceptions of the disease, awareness of availability of treatment, what people think would be the outcome of treatment or non-treatment, among other things. As Sugar et al (1994) point out, the factors impinging on care seeking are many and include: “ .. belief systems and stigma attached to particular symptoms, previous experiences in seeking care in the household and from others, expectations about seriousness and outcome, accessibility of different care providers, and educational and economic levels..” These, far from being isolated variables, are related.

More than half the affected sample thought the lesions were very serious but the non-affected rate them even more severe. When we compared these findings to those obtained from other African sites where the same sets of questionnaire were used to collect information on onchocercal skin disease we notice the same pattern reflecting respondents’ belief that these were indeed serious and severe conditions. This is not to deny the objection that to some people every illness is a serious matter anyway. We think that is a minority position however. Of the four lesions discussed the Ghanaian affected sample viewed DPGM as least severe and LOD as most severe.

Most affected people thought there was treatment for their condition, even if they did not always admit to knowing where that treatment is located. There is however, relatively more uncertainty about the availability of treatment for DPGM.

Table 4: Availability of Effective Treatment for OSD
(The Perceptions of Non-Affected Ghanaian Skin Study Sample)
EFFECTIVE TREATMENT

LESION	Yes	%	No	Poss	Uncert	Total
CPOD	63	(94.0)	0	3	1	67
DPGM	33	(80.5)	4	1	3	41
Total	96	(87.9)	4	4	4	108

Most affected and non-affected Ghanaian respondents agreed that effective treatment existed for onchocercal skin lesions. Table 5 shows the overwhelming optimism of the non-affected. Not only was it the view of the sample that effective treatment existed respondents were optimistic that with the right treatment the affected would be cured. Again, there were more doubts where DPGM was concerned.

Table 5: Perceived Outcome of OSD Treatment
(The Perspectives of Affected Ghanaian Skin Study Sample)

LESION	Uncert	Cure	%	Improve	Total
APOD	2	8	(80.0)	0	10
CPOD	2	31	(91.2)	1	34
DPGM	3	20	(71.4)	5	28
LOD	1	20	(90.9)	1	22
Total	8	79	(80.0)	7	94

The findings suggest a high level of confidence in both categories of respondents, and by implication the communities can be said to hold the view that not only is there effective treatment people would be cured if they were treated. Findings on the question of what the outcome might be if the conditions in question were not treated is in Table 6.

Only one affected person expected that even without treatment the condition would heal. A few expected that the condition would stabilise. However, most people were of the view that it would develop with time into something more sinister unless treated. The findings for the non-affected are somewhat dissimilar. As non-affected, they were less embarrassed to speak out and consequently nobody seemed to doubt the possible outcome. None thought the condition would heal by itself. A quarter of the sample expected the affected person to be killed eventually by the disease, a view which only one affected person shared. Non-affected men seemed more sombre about the outcome of failure to treat the disease.

Table 6: Perceived Outcome of OSD Non-treatment
(The Perspectives of the Affected at Ghanaian Skin Study Sites)

LESION	NON-TREATMENT OUTCOME								Others Total
	Uncert	Cure	Stable	Worsen	Serious	Disable	Fatal		
APOD	2	0	2	3 (30.0%)	3	0	0	0	10
CPOD	3	1	3	20 (58.8%)	5	0	1	1	34
DPGM	2	0	8	17 (60.7%)	1	0	0	0	28
LOD	0	0	0	16 (76.2%)	3	2	0	0	21
Total	7	1	13	56 (60.2%)	12			2	1
									93

At this point the conclusion is that onchocercal skin conditions are a serious matter and unless something is done about them the future does not bode well for the affected. As Awedoba and Hagan (op cit) shows respondents expected that the biomedical facility more than any other would provide the right treatment. More of the non-affected seemed to articulate these views than the affected themselves.

Given these findings, one tentative conclusion emerging is that the affected would seek treatment and they would be encouraged by their non-affected associates to do so. Furthermore, they would seek this help from the biomedical facility^{viii}. It is also to be expected that the affected who thought LOD would benefit most from treatment would be more likely to seek treat for the condition than would be the case for DPGM. These expectations were not however met when respondents answered questions concerning their past help-seeking behaviours. Perhaps this confirms Yoder's (1997:132) warning that we must not expect a close interdependence between behaviour and knowledge, a point implied in Young (1981) criticism of the rationality of health seeking behaviour.

^{viii} We admit that some of the affected were not sure that the local facilities in the District would be helpful and a number of respondents had in fact remarked that they had sent their problem to the hospital but obtained nothing more than temporary relief.

Perceived Cause of Onchocercal Skin Disease:

The perceived causes of onchocercal skin conditions elicited from both affected and non-affected are many; however, insects, particularly the black fly (although there has been mention of mosquitoes and tsetse flies and other bugs), effect of vegetation, worms and parasites as well as blood related problems, the rivers and drinking water feature prominently. Unlike other African sites where witchcraft and ritual causes were cited by 10% of the sample as important causes of onchocercal skin diseases, Ghanaian samples perceived mainly physical causes for these conditions. The factors regarded as most important were drinking water and insect bites.

The comments of Ghanaian respondents illustrate the variation that exists between respondents. While some admitted to not knowing the causes there were also others who suggested more than one agent, often pointing out how several causes operated sequentially or concurrently to bring about the illness conditions in question.

Help-Seeking for Onchocercal Skin Disease

Respondents admitted that they did not all find the various types of help-seeking that they had used in the past beneficial, see Table 7 below. While for general help-seeking for all cases of ill-health, as Tables 1 and 2 above reflect, drugstores are most often relied upon, responses for help-seeking specific to onchocercal disease suggest that self-help and home care are more frequently used than drugstores. The reduced importance of drugstores in help-seeking for onchocercal conditions can be attributed to the inability of the affected or their family and associates to determine what pharmaceuticals are efficacious for these conditions.

Table 7: Probed Help-Seeking and Usefulness
(Views of Affected Ghanaian Skin Study Sample)

TYPE	USED		USEFULNESS	
	Freq	PCT	Freq	PCT
Self	45	47.9	53	39.3
Home	22	23.4	20	30.3
Friends & Rel	4	4.3	6	50.0
Chemists etc	16	17.0	21	46.7
Bio-Medical	26	27.7	54	72.0
Trad Healer	5	5.3	4	33.3
Faith-Healer	1	1.1	1	33.3

☞ Figures for “Usefulness” are weighted. “yes” scores 3, “mixed possible” scores 1 and zero for “uncertain” and a “no” response. The Percentage score is based on the maximum (i.e. all cases saying “yes” and scoring 3 for usefulness).

Traditional Healer: These are professionals in their own right, some of whom as Twumasi (1987)

has pointed out, have been trained for their job. The majority of respondents did not think they are capable of treating onchocercal conditions successfully since these are regarded as of non-spiritual causation. Nevertheless some respondents have made use of their help.

Female, CPOD, 44 yrs old: “At first, I did not believe it to be a very serious condition, but when I realized that I was growing lean, I decided to consult a diviner, but even there I was not satisfied with what he told me. For he told me that 'itching skin' was an [physical] illness. So my husband then said if it is an [physical] illness, then I should take it to hospital.”

Reliance on the Drug sellers: Included in the category of drug seller, are untrained persons operating from fixed addresses (stores or stalls on the street) from which drugs are sold on demand or on the drugstore keeper’s recommendation, as well as sellers in vans that rove from village to village hawking medications of local manufacture and finally, the individual who hops from commercial passenger vehicle to the next doing business with the travelling public.

CPOD Respondent: “I once bought an ointment from a roving drug pedlar selling his drugs in a bus which I have applied to the condition”

CPOD, 72 yr old woman: “I usually buy some tablets like indocin, M & B, codeine, ampicillin etc for reducing the itching and sores”

Local people tend to buy their medications across the counter rather than depend on a drugstore keeper who, the community know, has no training for dispensing medications. Thus, the utility of the drugstore declines for those who do not have confidence in the drugseller but could not on the other hand determine what pharmaceuticals would be effective for onchocercal skin conditions.

Use of Herbal Preparations: Herbal here refers to plant or vegetable substances that respondents say they have used to treat their onchocercal lesion and itching. Items included various leaves and the residue from palm kernel after it has been boiled and the oil extracted leaving the fibrous tissue (**mefe**). Substances may be processed, as some of the comments show, before being applied topically to the affected area. In some cases the substances were boiled and the liquid infusion used as an enema i.e, introduced into the system rectally.

69 year old, with DPGM: “I use 'bondo', a plant leaf. I suspend it on fire and then daub it in ashes before applying it to the surface of the skin. It has the effect of reducing the itch”

20 years old female, LOD: “When I am preparing palm nut soup, I rub the affected part with some of the pounded palm nut.”

41 year old female CPOD: “I have used the local herbs provided by my husband to syringe”

34 year old LOD: “I have been using 'mefe' to treat it and this was recommended to me when I discussed my condition with friends. I have been trying to get money so as to take it to the hospital for treatment but I have not yet obtained enough”.

Experimenting with Mixtures: The comment below illustrates the creativity of affected people in the concoction of a treatment. Drugs might be mixed or combined with herbal substances, as the comment shows.

30 year old man: “I used ampicillin and terramycin capsules, mixed them with palm kernel oil and applied this solution to the condition. This eventually helped to stop the itch.”

Hospital Treatments: A 24 year old female with CPOD comments as follows: “I think whiteman's doctors can treat this condition because it may be that the condition is caused by germs and only the hospital can treat such conditions”. This is a view shared by this 60 year old man with DPGM who remarks: “I think doctors can treat this condition because I think it is due to germs. It started with an itch and germs are known to cause itching. Only doctors can treat diseases that are caused by germs”.

Doctors have responded to these complaints by providing drugs and ointments as the comments cited below reveal. The better equipped facilities might recommend laboratory tests prior to prescription of medication.

60 years old male DPGM: “I went to hospital when the black coloration had appeared. I was given ointment to apply and when I applied it the colour changed to 'red'”

38 years old male CPOD: “I have gone [been to] to the Enchi hospital, where I was given medicine to take but the condition still persists”

42 year old male, LOD: “I have taken it to the Cape Coast Eye Clinic where I was fully examined by the doctor and subsequently referred to the Laboratory for tests. Unfortunately, I could not go to the lab as my money had run out”

An examination of respondents' comments suggest that the hospital visits have not guaranteed relief and that there is some skepticism. Comments typify what outcomes some affected experience on these visits and levels of patient satisfaction. Problems included the perceived worsening of the

condition after hospital treatment, the lack of money to meet the cost of laboratory tests and doctor absenteeism. Unpleasant experiences such as these can explain the unwillingness to present onchocercal conditions to the hospitals, even when there is a feeling that biomedical approaches are the best option available.

Hot Bath Complex as Self-Help for Itching: The more or less routine toilet behaviour of a hot water bath becomes a mode for dealing with certain health issues including itching. Water used may be ordinary water or an infusion of herbs and leaves; in some cases salt is added to the water. The bath may be accompanied by use of ordinary soap or special soaps. After the bath the body, particularly the affected regions of the body, might be treated with ointments, powders or herbal preparations deemed beneficial to the person who suffers an itch. Individuals vary as to what goes into their “hot bath complex”. As illustrated below.

38 year old woman: “Whenever I use hot water to bathe and then daub the surface of the condition with lotus powder it reduces the itching and makes me feel a bit relieved. This however is a temporary solution”

38 year old female: “If I use the boiling water to which salt has been added, the spots disappear for sometime but re-appear later. The same goes for the drugs I buy from the drug-store.”

Dependence on Antiseptic Soaps and Cosmetics: Popular medicated and antiseptic soaps in Ghana include Asepso soap, Camel antiseptic soap and other manufactured products sold in the shops but **alata samina**, also known as **kotokoli**, (names which suggest its foreign origins) which is made locally is even more popular because it is believed to have a very beneficial effect on the skin.

25 year old female CPOD: “ People say Cleartone (type of cream used by Ghanaian women for skin bleaching) is good for it so I have been using it to apply on the affected parts.”

33 years old male CPOD : “ I used some locally made soap (Alata Samina) to wash the arms and limbs and the rest of the body”.

CPOD 16 years old girl: “I use "alata" soap - a locally made soap useful as a medicine - to treat the condition”

Ingestion of Fluids and Others: Respondent with DPGM: “I have been sucking ordinary salt to reduce the itching when it becomes serious. This was recommended by friends”

26 yrs old LOD: “ I have used lime to treat the condition. I drink it and apply some of the lime liquid to the affected parts. I started using the lime treatment about a year ago and I still use it”

These remarks are illustrations of the kinds of help-seeking that affected people have reported using and they go to support the statistical tables presented above. The expectation of affected respondents is to seek a cure or temporary relief from the condition in its entirety or its worrisome symptoms such as the rashes, the outward appearance of the lesions such as the colour changes. What comes through from these comments is their eclectic nature. The affected are prepared to do what it takes to secure the much desired cure and healing. Help-seeking modes are thus not regarded as irreconcilable or mutually exclusive, a confirmation some reearchers' conclusions on the subject; see for example Pelto et al.(1990) "eclectic opportunism".

Treatment of Itching:

The aspect of onchocercal skin disease that worried affected people most was the itching that is commonly associated with the condition.

Table 8: Symptoms Mentioned by Ghanaian Affected Sample

SYMPTOMS	CPOD (N=34)		DPGM (N=28)		L OD (N=22)		APOD (N=10)		TOTAL	
	Freq	PCT	Freq	PCT	Freq	PCT	Freq	PCT		
Itching	31	91.2	15	53.6	17	77.3	4	40.0	75	79.8
Appearance	7	20.6	6	21.4	9	40.9	2	20.0	21	22.3
Insomnia	5	17.7	3	10.7	4	13.6	0	0.0	12	12.8
Headache	3	8.8	2	7.1	1	4.5	1	10.0	7	7.4

Itching reportedly affected work and concentration as it compelled the affected to interrupt whatever they might be doing to scratch themselves. Furthermore scratching ruins the skin causing laceration and making it rough with sores and ugly scratch marks. At night itching keeps people awake and by day break they fell tired and sometimes have headaches. 44 of the non-affected respondents interviewed on CPOD or 66.7% and 26 or 63.4% of the sample interviewed for DPGM mentioned itching in their comments on the effects of onchocercal skin disease. In the case of the affected almost 80% complained about itching.

The suffering that is entailed compels the affected to do something about it. Table 9 below shows what a set of respondents who have admitted to having itching in some southwestern Ghanaian river basin communities did do to relieve the suffering. Although we do not have comparable figures for the other Ghanaian sites, the Southwestern Ghanaian river basin communities are very representative

of the other study sites.

Table 9: Help-Seeking for Itching

(Respondents from SW Ghanaian River Basin Communities)

Help-Seeking	Main		Secondary		Aggregate	
	Freq	Pct	Freq	Pct	Freq	Pct
Drugs	60	19.5%	38	24.7%	158	20.5%
Medicated Soap	58	18.8%	34	22.1%	150	19.5%
Bio-Medical Help	58	18.8%	38	24.7%	154	20.0%
Home Care	25	8.1%	32	20.8%	82	10.6%
Dustin Powder	4	1.3%	5	3.2%	13	1.7%
Uncertain	3	1.0%	2	1.3%	8	1.0%
Oncho Program	2	0.6%	4	2.6%	8	1.0%
Trad Healer	-	-	1	0.6%	1	0.1%
Nothing	98	31.8%	-	-	196	25.5%
Total	308	100.0%	154	100.0%	770	100.0

Self-help and home care together account for the bulk of help-seeking for onchocercal skin disease. The affected have used drugs purchased from the drugstore on advice or across the counter, they have bought various soaps, particularly the local antiseptic soaps and powders, local ointments and herbal recipes. A number of them have also visited hospitals and clinics to seek treatment.

Of those reporting use of chemotherapy, more than 4 out of 10 could not remember the names of the drugs they received for treatment. The names and descriptions of drugs used by respondents would suggest that Ivermectin and antizan were received as treatment from either a medical facility or a drugstore. It was found that DEC (banocide) which has since been disrecommended as a treatment for onchocerciasis continues to be used^{ix}.

Table 10: Drugs used to Treat Itching

(Respondents from SW Ghanaian River Basin Communities)

DRUG NAME	Main		Secondary	
	Freq	Pct	Freq	Pct
Antizan	19	10.9%	3	5.3%
Ivermectin	14	8.0%	5	8.8%
Ointment	8	4.6%	7	12.3%
Paracetamol	7	4.0%	7	12.3%
Other	47	26.9%	16	28.1%
D.K. Name	76	43.4%	19	33.3%
Banocide	4	2.3%	-	-

^{ix} The principal investigator for the research project, an ophthalmologist, is unhappy about this state of affairs, especially as in some cases DEC (banocide) seemed to have been prescribed by a physician.

-----+-----
Total | 175 100.0% 57 100%

(Note: **Main** refers to first mention while **secondary** refers to subsequent mentions which come as an afterthought)

Coping with OSD at Ghanaian Skin Study Sites:

In addition to seeking treatment there are sundry other ways in which the affected deal with onchocercal skin disease particularly, its two most important perceived symptoms: itching and the unsightly appearance of the skin. Scratching is a normal response to itching but the manner in which this is done also reflects the individuals way of coping with itching. First of all it should be remarked that some of the affected by their own admission see scratching as a way of coping. This provides temporary relief but is not expected to cure the itch of the condition in its entirety. As would be expected most people scratch their bodies with their fingers. However, various devices came in handy. These include the use of brooms, cutlasses, combs, stones, sponges, the cobs of corn and other abrasive instruments. Some people suspend the itchy parts over fire to burn off the itch, as it were the itch. Individuals have reported that sometimes the result of scratching is bleeding and a damaged skin surface. Thus when scratching is intense it provokes sympathy and disgust in onlookers.

Coping Negatively:

Negative coping strategies often reflect the perception of stigma due to the lesions. They include attempts to classify or label an onchocercal skin disease as non-disease. This is effected in a number of ways aimed at denial and refusal to accept or admit publicly to having the disease or its symptoms. It is pertinent to remark that no non-affected person has suggested in any way that the skin diseases in question were anything but pathological conditions.

Presenting DPGM as Scars:

Some respondents, albeit the minority, refused to accept the diagnosis of the physician. The common argument has been that the lesions resulted from ordinary wounds that they had sustained in the past which on healing left scars. It is possible that errors could have been made in the physical examination since to the ordinary or untrained person, scars on the lower feet would be almost indistinguishable from scars from ordinary wounds. However, it must also be pointed out that the definition of DPGM suggested by Murdoch et al (1993) and by others uses specific characteristics

which study physicians could recognise^x. It cannot be discounted that respondents who insisted that their lesions were scars were misleading the investigators. In the Ghanaian setting, a person is not exculpated entirely for contracting a disease. The beliefs on the causes of onchocercal skin disease, as showed in this paper, are many and include those that assign some responsibility to the affected person or that person's kin. What is more, beliefs on the transmission of onchocercal skin disease by heredity and personal contact imply that the affected has not only been responsible for the disease but that he or she remains a danger to others in the community. These are all grounds for labelling a lesion as non-disease. Denial may thus be a way to cope with the stigma due to the condition; see Ovuga et al (1995) for a similar conclusion drawn for Ugandan affected respondents' attitudes to onchocercal skin disease.

Presenting papular rashes as having healed:

Some cases of CPOD have been described by the affected as having healed since, they maintained, it had ceased to be a bother to them. This attitude is not too different from that of the DPGM affected person who attributes the lesions to some other event. To prove that one's illness condition has healed is to claim some credit, vicariously or otherwise, for the turn out of affairs, even if others share in the success. As has been remarked by one respondent, persistence of a condition can be put to the neglect of the affected person or kin to deal with the problem; so therefore a cure should redound to the patient. Secondly, a healed condition revokes the stigma that the affected may once have been subjected to.

Skin changes attributed to old age:

Ugly scars are believed to ruin a person's physical beauty^{xi}. The stigma is greatest however with DPGM when it is perceived as a manifestation of disease. However, attributing the disease to ageing becomes a possible strategy for reducing the stigma due to DPGM. There is a local realisation that DPGM is common with older persons in these communities where seniority in age happens to enhance respect and social status. Thus it becomes possible for some of the affected to reduce the

^x The participating physicians were trained at a workshop in Ibadan, Nigeria, specifically on the identification and grading of onchocercal skin lesions prior to the study.

^{xi} This is hinted at in a favourite folktale recounted by the Kasena of Upper Eastern Ghana which criticises a maid who would not marry anybody with a scar on his body.

stigma due to the condition by associating it with old age. In fact when accepted as a sign of ageing the affected might exhibit the condition and not feel much shame. At the Awka site in the Nigerian state of Awka-Ibom, DPGM is associated with agricultural success by some respondents (personal communication of principal investigator for Awka). In deed, if it is the case that severe manifestation of onchocerciasis is associated in some way with occupation, as some findings have suggested then, onchocercal skin disease may affect those more enterprising and harder working farmers than those who shun the more fertile river valleys where the fly also happens to abound^{xii}.

LOD Described as Birthmarks:

Just as CPOD and DPGM have been described as non-pathological so also with Lichenified onchodermatitis which a respondent described as a birthmark. LOD shows up in affected people as darkened patches of the skin which also becomes somewhat thickened. Though a birthmark may manifest in spotty skin pigmentation it is rarely associated with thickening of the affected area. Very visible birthmarks may indeed draw stigma but this is mitigated by their acceptance as the work of heaven. The readiness of some affected persons to attribute LOD to birthmarks goes to illustrate the burden of stigma felt for LOD.

APOD and CPOD Described as Heat rashes:

Heat rashes are not normally perceived as manifestation of illness in Ghanaian communities. They are viewed as fleeting episodes that do not linger. Moreover, it is believed that anybody may be susceptible in the warm climate. As they are moreover not normally seem as transmissible from person to person, they do not therefore carry a stigma or illness burden. Thus, by labelling a papular rash as heat rashes, the affected are resorting to a common coping strategy, a form of denial.

^{xii} Working close to the breeding sites of the black fly means receiving frequent bites. The findings of Workneh et al (1993) in Ethiopia do not however suggest that the affected are more enterprising, rather they absent themselves more frequently from work, a fact that has been attributed to a lowered capacity for work due to chronic poor for which the disease is responsible.

13. Comparable findings on severity do not exist for the Ivermectin study sites but the Skin study and Ivermectin Study communities' findings on the psycho-social effects of the disease have been compared and discussed in Awedoba and Hagan (op cit).

OSD As Condition That Will Heal Without Treatment:

Another way of coping is to accept that an OSD is a disease but of the type that would heal spontaneously and therefore requiring no treatment. A condition that requires no treatment is viewed as either non-pathological or one that is self limiting, at worse a marginal condition or just a temporary nuisance. Included in this category are the 26.6% affected (compare with only 4.3% of the non-affected) who label their onchocercal skin condition as not serious. An individual thought his condition would improve without treatment and 13 others expected the lesions to stabilise without treatment.

Concealment and Unwillingness to Disclose condition:

Self perceived stigma has been established in this study by eliciting views of the affected on whether it is “.. important to you to keep people from knowing about this condition?” and secondly if there is anyone whom the affected would like to know about the condition. While most people, i.e. 72.3% of the affected sample, do not mind letting people know that the condition is on their person, 25.5% of the sample are averse to this. They would conceal the fact, if the matter rested with them personally and in addition to their unwillingness to disclose information on the condition they would also take several measures to keep others from knowing about the condition.

Concealment of evidence of the condition can take several forms. Wearing long sleeves shirts to cover the arms and the upper parts of the body or being in trousers most of the time or in the case of women, wearing dresses that reach to the feet and cover the arms are all variations on a theme and are aimed at concealment. They have been suggested by affected and non-affected alike, particularly the latter.

Denial of Scratch Behaviour:

There ambivalence about scratching; for some it is unapproved socially, especially when the scratching is aggressive, takes place in public places or compels the affected to use abrasive instruments to scratch in public or in the presence of non-kin. As one of the phrases that describe onchocercal skin disease suggests, itching makes people seem inattentive to their interlocutors, see Awedoba and Hagan (op cit). It seems to follow therefore that affected people would deny that they itch or that they engaged in scratching themselves. Some respondents maintained that scratch

behaviour is unsightly, others said it is impolite while some opinions maintained that it is unhygienic.

Avoidance of Public:

A number of respondents maintained that they did not experience itching in public but that if they did they would rather leave to be able to indulge their urge in private. Those who deny scratching in public or even having to scratch at all claim that itching occurred at night or at bedtimes, at the farm when working or under the influence of inclement weather (exposure to rain). These are in many cases alibis; they imply that itching in public and the question of scratching oneself in public often did not arise for some affected persons. We are here dealing with private experiences that the respondent knows the researcher cannot contradict. These denials can serve to protect an affected person's face vis a vis the knowledge that scratching in public is unethical. We have here a classic illustration of the distinctions between what people say they do, what they say they ought to do and what they actually do. Although we cannot deny that a person is telling the truth when he denies feeling the itch in public we cannot help but observe a discrepancy between utterance and behaviour in a person who continues to scratch away as he makes his denial.

Coping Passively:

Finally, it should be pointed out that some affected people have got to the point where they no longer bother to consult healers of any description. The perception of this group is that help is not available from local sources, a conclusion based on experience. Included in this category are those who have failed to obtain satisfaction from the available help-seeking modes. Some in this category believe that their onchocercal skin condition, especially in the case of DPGM, is not treatable while others who may not discount the possibility of there being treatment somewhere feel it does not matter anymore. The aged who might feel a general despondence or are depressed with life as a whole belong in this category as do those who maintained that they were too poor to afford the means to seek organised help-seeking.

Discussion and Conclusions:

It is pertinent that we consider the findings discussed above against the background that this is a disease associated with isolated small communities that are rural where modern health facilities such

as hospitals are scarce, if not unavailable. Located close to rivers, a habitat that favours the vector fly, the physical features of the terrain contribute further to the isolation of endemic communities, as road construction and maintenance are hard to sustain. Isolation often makes such communities unattractive to those with voice and potential to invest in the general welfare of the communities while chronic ill-health to which onchocerciasis is a contributor exacerbates the community problems. It is the continuous exposure to the bite of the infected flies which is responsible for the chronic conditions that are discussed here.

DNA tests show differences between antigens in the forest and savannah ecologies. While blinding onchocerciasis associated with the savannah ecology attracts sympathy, for example the Merck donation of Ivermectin was in response to blindness, in the forest zones where the researches discussed here were conducted, it is the skin problems and itching, conditions official attitudes treat as marginal, which are significant. These, however, have a tremendous effect on the quality of life of the affected. They cause suffering as well as stigma and contribute to general poor health as research in Ghana and other African countries has shown.

By examining the question of how local communities and individuals cope with specific lesions and their effects, research that combines qualitative and quantitative approaches judiciously helps to highlight the burden of the disease on communities and individuals. This after all, is a condition that has a social dimension. An insight into local people's perceptions of the disease is not only necessary but valuable. Consideration of its causes and associated questions and what people do to treat the condition and to cope with the suffering that results can suggest the strategies and directions for intervention. As discussed above affected respondents demonstrate their ingenuity in the search for treatment in ways that suggest that they would be willing to accept initiatives that can be demonstrated to work. Many traditional societies are not as conservative as it might at first seem and nowhere is this more so than in the domain of health. It is common experience that people in Ghana, as elsewhere in Africa, are ready to compromise even religious beliefs for the sake of health, as exemplified by the inroads that African churches that incorporate healing have made at the expense of orthodox churches that have shunned healing rituals.

The study has pointed to intra-cultural differences as well as differences between affected and non-affected and between types of lesions. No attempt was however made to measure the effect of educational status on knowledge of causes and help-seeking behaviours. Non-affected people would tend to rate these diseases as much more severe than would the affected themselves. It would seem that the greater the distance between a person and an onchocercal skin disease the severer that condition appears to be and the greater the social stigma that the condition seems to provoke for the affected person. This conclusion is supported by a comparison of the views of affected and non-affected and those of meso-endemic (skin study sites) and hyper-endemic communities (Ivermectin study communities)^{xiii}.

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The sundry ways in which the affected cope with these conditions point to the burden of the problem on the life of the affected and it calls for concerted action from all players in the search for solutions to these and allied health issues that rural people suffer. Coping, just as in the case of a person's responses to a somatic disease, Lipowski (1969:1198), is more an individual's reaction to suffering than a collective one. This is not to deny the effect of the external symptoms of onchocercal skin disease on others, a fact that the affected themselves have remarked. The roots of coping go back to the society; it is determined and shaped by many variables including personality, status, etiquette,

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environment, and the nature of the pathological process. Affected people can be expected to cope with the disease, as they do, in various ways that are meaningful to them in the first place and to their communities.

An examination of the verbatim comments and remarks show that the modes of coping concern itching and the ugly appearance of the skin. Those who cope negatively keep others from knowing that they have the condition. They do so by covering the lesions and ensuring that they are not exposed to view, especially in public. Those who cope passively no longer wish to seek treatment for the condition and adopt fatalistic attitudes. This might result from failure in the past to secure effective treatment, although depression due to ageing cannot be ruled out for the older respondents with DPGM. On the other end of the spectrum are those who cope positively by seeking some form of treatment. It is generally accepted that bio-medical facilities are the best means for treating these conditions, however, there is less evidence that these conditions are sent to hospitals. This is because hospitals are not available locally and unless a disease is regarded as fatal or disabling it is unlikely to be sent to the hospital. Onchocercal skin diseases do not fall into these categories. Nevertheless some of those who have been bothered by itching have sent the condition to a hospital in the District or Region or in another Region of the country. These facilities have not afforded a lasting cure to the problem and this contributes to furthering despondency and a feeling that effective treatment is not available locally. Hospitals and clinics cannot escape a share of the blame for loss of confidence in these facilities in some rural areas.

In recent years there had been an interest in dealing with onchocerciasis in those endemic communities of southern Ghana which fall outside the direct purview of OCP. By creating a directorship for onchocerciasis, the Ghana Ministry of Health signals that it takes the disease seriously. Additionally NGOs like Sight Savers and World Vision have provided support for the distribution of Ivermectin in some of the communities. These well-meaning efforts however, need to be sustained. The chances of this happening are a lot better when alliances are established with the endemic communities, perhaps along the lines urged by Kleinman et al (1978) who also advises that of such models should take into account etiology, symptom onset, pathophysiology, the course of the illness and treatment, Kleinman et al (op cit: 256). A comparison of biological explanatory models

and their alternatives ascertained for local communities and individuals would show differences and areas of agreement. This should be the background against which messages and strategies for negotiation and education could be determined.

Negotiation and the involvement of affected communities may be necessary in the effort to contain onchocerciasis. Efforts are being made to determine the modalities for carrying out what, in WHO parlance, has come to be known as Community Directed Treatment with Ivermectin. For such a scheme to succeed knowledge of the communities' perspectives on the disease is crucial. Answers to questions such as severity and seriousness of onchocerciasis, where onchocerciasis fits into a community's scheme of priorities, a community's management of the disease, and how far they are willing to stretch to accommodate the burden of self direction of mass treatment are necessary even before we attempt to introduce such programmes.

A community that holds the belief that skin diseases such as onchocercal skin ones and their associated symptoms such as itching are just a nuisance and nothing more may be unlikely to commit scarce local resources such as the time and efforts of individuals or provide the incentives that would encourage the emergence of leaders who receive no external material reward for their services. Secondly, a community that believes that the cause of onchocercal problems is the drinking water may call for an improvement in the quality of drinking water. It may wish to see the affected treated as a matter of course. All this implies that any scheme that moots the idea of mass treatment with Ivermectin and its side effects, mild as they might be, will be misunderstood. We are here echoing ideas that some respondents have advanced for the containment of the disease, see Chapter four in Awedoba and Hagan (op cit). The success of the programme might also be influenced by local attitudes to chemotherapy and Ivermectin in particular, especially when considered in the context of the drug use (or abuse) without professional supervision. Some of the comments cited above suggest that a form of iatrogenesis occurs in the study communities, where drugs may be used more or less like panaceas. Indomethacin is so used and Ivermectin which earned the praises of local communities where the Ivermectin trials took place too has the potential to evolve into such a panacea. The result would be that it could become a marketable commodity diverted elsewhere or consumed more regularly in responses to other ailments. Should that happen the long term effects would be

unpredictable, quite apart from the likelihood of the drug being diverted from the needy and sold elsewhere.

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