

Podoconiosis in the Dembidollo and Nekemte area, West-Ethiopia 2011

Report on the visit in January-February 2011

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INTRODUCTION

This report describes our activities during our Ethiopia visit in January/February 2011. We visited the mission clinics in the Dembidollo and in the Nekemte area. We also visited the Gimby and Aira hospitals. We had a meeting at the Wollega university in Nekemte. In Addis we had a meeting at the IODCC with other people involved with podoconiosis and we had a meeting at the Ministry of Health.

Including our visits in 2005 and 2007 this was the third visit of the complete team. In the intervening years the clinics are visited at least once a year by one or two of the board members of the Wollega-Ethiopia foundation to discuss the micro credit program and evaluate the podoconiosis program.

In March 2005, on request of the health workers of the 9 Mission Clinics in the Dembidollo and Nekemte area, we visited this region for the first time and did a survey to get a better understanding of elephantiasis in the area. Further investigation and contacts in The Netherlands and abroad revealed that the altitude of the region and the clinical features make podoconiosis (non-filarial elephantiasis) the certain cause for elephantiasis in this region. In 2007 this was confirmed by discussions with Dr Gail Davey, at that time epidemiologist at Addis Ababa University. Together with her we visited the Mossy Foot project in Sodo, Wolaitta, an area south-west of Addis Ababa where podoconiosis is also endemic. In the last 5 years Dr Gail Davey and others have published many articles on podoconiosis. Worldwide attention came recently as the WHO put this disease on the list of neglected diseases. (see http://www.who.int/neglected_diseases/diseases/podoconiosis/en/) .

PODOCONIOSIS



Research revealed that podoconiosis is probably the result of a genetically determined abnormal inflammatory reaction to mineral particles in irritant red volcanic soil. This means that the disease can be prevented by cleaning feet and wearing shoes from young childhood. This is especially important for children in families which are affected by this disease.

For patients who are already affected by podoconiosis secondary prevention is very important. This includes (the same as for all other causes of lymph edema): daily foot washing with water, soap and antiseptic (bleach, potassium permanganate, neem leaves), use of an emollient (Whitfield ointment, neem oil). For some patients, especially in early stages, bandaging can be useful. For all patients

simple exercises and elevation of the leg are important. And of course all patients should wear socks and shoes to prevent further contact with the soil and to prevent wounds and infections.

There is no specific medical treatment for podoconiosis. Infections (fungal and bacterial) should be treated. Surgical removal of nodules is possible for those patients who, due to some big nodules, do not fit into (specially adapted) shoes. More extensive surgery is not recommended.

HEALTH CLINICS IN WOLLEGA, WEST-ETHIOPIA

The health clinics we visited this time are almost the same as in 2005 and 2007. Five health clinics are located in the villages Sakko, Karro, Addo, Alequ and Danka, all around Dembidollo (alt 1700 m), the capital of West Wollega, 650 km west of Addis Ababa. The other clinics are in Konchi, Aria Jawi and Gute Abekuna, all around Nekemte (alt 2000 m), the capital of East Wollega, 330 km west of Addis. In some clinics the nurses invited patients. We examined them individually and discussed their condition with health workers. In other clinics we just discussed with the clinic staff about their experiences with podoconiosis.

In Addo we attended the regular education program for a group of patients. An enthusiastic professional health animator talked for and with an audience of ca 80 patients. It took the form of questions and answers. He used an education leaflet from Wollayta, translated in Oromo language. He stressed prevention for children and early treatment. We heard stories from very happy patients: no smelling anymore, less swelling, wearing shoes, feeling much better, no longer afraid of other people, not covering and hiding themselves anymore, participating in normal social life. The health animator encouraged patients to spread the information to others.

Near Karro we also visited Lagalomi, since one year a resettlement village of people from the Harar area (east Ethiopia). in Lagalomi no podoconiosis has been seen until now. We stressed the importance of education on podo in this settlement to prevent podo in the future.

Podoconiosis programs



In all clinics the staff and patients tell us that they are satisfied with the results of their treatment and educational activities. Thanks to the stories of satisfied patients still new patients come to the clinics, often with a history of many (expensive) treatments of traditional healers, doctors and other clinics without results. This makes it clear that there is still a lot of work to do to make this preventable

disease also more well known to other health workers. The clinics report that the Government Health Centers do not have any activities for podoconiosis.

The podoconiosis programs of the clinics do not differ much. Most of the clinics have weekly a specific day for podoconiosis patients, so that they have 4 groups of patients who come every month to the clinic. In total the clinics cover each month many hundreds up to thousand patients in their program. In the rainy season fewer patients show up but the clinics do not have the impression that after the rainy season the condition of the patients is deteriorated. All clinics give extensive education. In all clinics and health posts the poster with educational pictures in Oromo text we made after our last visit, is used.

All clinics dispend basins, soap, antiseptic, emollient. Sometimes for free, others ask a small contribution. The antiseptic which they use is often related to their (donating) relations: the Indian nurses get potassium permanganate from India (which makes this cheaper than the local bleach (barakina)), one clinic (Danka) uses powder bleach, donated to them, in large tins from the US army. One clinic (Gute Abekuna) uses kurkuma. Also the emollients differ: neem oil (works also as an antiseptic), Whitfield ointment (also antifungal).

There is a big difference in the use of antibiotic treatment between the clinics. There is still wide spread use of antibiotic treatment, mostly benzathine penicillin. However some clinics tell us that they have reduced this by more than 50% since they started with their podoconiosis program. Especially for people who come from far away they are quicker to use antibiotic treatment because they “do not want them to become more ill”. Indications for prescription of antibiotics differ from fever and severe illness to just “bad smell”.

There is still a misunderstanding about skin snip tests “for filariasis” in some clinics. Almost always with negative results. This negative result is probably due to good coverage of the mass treatment for onchocerciasis by the government (for an explanation on this skin snip test see attachment 2). No clinics reported to have seen edema above the knee, so it seems still very unlikely that in this region lymphatic filariasis is a cause for elephantiasis. One clinic (Danka) reports 3 patients (all women, 28, 35 and 45 yrs old) with one swollen arm (one of them also with swollen legs). They do not work in the pottery industry, all are living nearby the clinic. We do not think that this condition is due to podoconiosis.

Some clinics used bandaging for selected patients (soft edema) and were very happy with the results. Often they had to stop this treatment due to lack of (good) bandages. Good bandages are very expensive and difficult to purchase in Ethiopia.

Lymph drainage is not used due to lack of enough knowledge and time. However all clinics advise simple lymph draining exercises. The sisters in Getema (Gute Abe Kuna Clinic) use a mechanical lymph drainage massage machine for just a few patients who live nearby their house.

Not all clinics check school children on a regular basis. Some combine this check with their goiter check and –education.

In Ethiopia the government has a network of health animators who educate on selected health topics in rural areas. In some areas now these health animators have also included podoconiosis in their education program. Some clinics cooperate with these health animators, some employ their own health animators. Clinic staff, health animators, women groups and students sometimes perform drama's on podoconiosis at schools and in villages. An education program on CD and video has been made by the health officer of the Danka clinic.

All clinics report that they still get new patients, most of them from far away, outside their “catchment area”. It is not clear if this is a result of the work of the health animators or if the message spread around by other patients. Some clinics report that they have the impression that only 10-25% of the patients in their area are seen in their clinic. Reasons might be ignorance, social isolation, fear of costs, shame, distance. The clinics think that there is much work to do in education further in the field for instance in Sasiga (20 km from Nekemte direction Gimbi) one of the nurses reports to have accidentally seen many patients. There is no clinic in that village.

There is also a suggestion to teach community leaders to spread the message, even to organize competitions. Due to lack of money they are not able to do this at present. Last year some schools, health workers and women organizations performed a drama on podoconiosis during the visit of the board members of the foundation Wollega-Ethiopia.

Wearing shoes is one of the measures to prevent podoconiosis. When people have shoes in Wollega they usually have plastic or canvas shoes. For patients with more swollen feet it is difficult to fit into shoes. Moreover for patients plastic shoes are making things worse: they cause sweaty and wet feet and fungal infections and due to sharp edges they make wounds. Some clinics supply canvas shoes for patients. For patients who do not fit into ready-made shoes there are 2 shoemakers (also patients) attached to clinics (Nekemte and Konchi) who make big leather shoes. Even these shoes are not bigger than size 45 which is sometimes not big enough. Other clinics are also interested in getting patients trained to be a shoemaker and in employing them for making and repairing special shoes.

Because there is an indication that there is a genetic predisposition to get podoconiosis, clinics advise patients to let their children wear shoes. A USA company, Toms Shoes, started a program to supply twice a year shoes for children of families who are affected by podoconiosis. The majority of the clinics work with this program. They experience that the shoes are of a very bad quality, do not last longer than 2-3 months. Moreover the shoes are made of plastic, a material we just try to avoid! Another problem with the Toms Shoes program is an effective education program. Prevention does not work without education. One clinic did not start with the Toms Shoes program since they thought it an inadequately considered program: not starting with education, plastic shoes, doubt on quality. Also the big Mossy Foot Program in Sodo/Wollayta did not start with the Toms Shoes program for these reasons.

Patients

In many clinics we saw patients and examined their feet. In total we saw around 100 patients. Most of them with good result of the treatment: clean, soft skin, dry feet, still with signs of podoconiosis but no smell, no fungal infections, even sometimes in patients with severe podoconiosis.



severe pododermatitis but clean!

We saw patients who were only for a few months in the program already with good results of sometimes intensive cleaning (starting with two times a day cleaning in the clinic during the first week). But we still saw also patients with smelly, dirty feet, fungal infections even after having been in the program for years.

In Konchi we saw 2 patients, both young women, who had surgery ca 2 years ago. Both of them had nodulectomy with skin graft on both feet. We compared their legs with pictures from before surgery. both were still less swollen than before treatment. One of the women often has pain in her lower legs, the other often has itching feelings. This last one was developing small nodules again in the area where she has been operated. both had very clean feet, soft, no fungal infections. Both women wear shoes and socks, they do not wear bandages or stockings due to non-availability.



after surgery

It was not always clear why, in a clinic, some patients are better than others and why in some clinics the results were better than in other clinics. It seems most important that patients are aware that they have to continue their program washing etc at home on a daily basis. For that they need to have a basin, soap, antiseptic and emollient at home. But most essential is the availability of water. Water is

scarce in Wollega. In some villages water taps are nearby but outside the villages women walk long distances for a can of water. Also patients and health workers should be aware that the (cheap) plastic shoes contribute to having sweaty and wet feet and fungal infections. For all patients continuous enthusiastic and stimulating education and supply of soap and antiseptic for daily use at home seem to be vital conditions to get and maintain any results.

HOSPITALS

On our way from Dembidollo to Nekemte we visited Aira and Gimby.

In Aira we met dr Erik Erichsen, originally a Danish surgeon, and his wife Sennait. He told us that the hospital gets more patients referred with podoconiosis since there are more podoconiosis programs in the area. Almost all operations he does, are nodulectomies. He also does (est. less than 5/yr) big debulking operations; he is not very happy doing this but feels he has little choice when amputation is the only (surgical) alternative. He has never seen any patient for follow up after surgery. They also have a problem with getting bandages; they only have bandages available when people from abroad bring them. We also talked about the Toms Shoes project: Dr Erichsen is strongly against the supply of the plastic shoes for children by Toms Shoes. It is his opinion and experience that plastic is the wrong material for shoes for these children.

In Gimby we met Monica en Scott Barlow, resp. podo program coordinator and nurse of the Gimby Adventist Hospital. In this hospital since 1 yr they have a podoconiosis program: over 960 patients treated with soap cream (expensive) and bleach. They tried bandaging but do not have the right bandages. They got some shoes donated from Keen USA, a good quality, quite closed sandals but they did not receive enough to dispense them to patients and children. For their remote clinics in the future they plan to use a camera with GPS for further location of patients. The surgeons in the hospital do nodulectomies; they do not do debulking operations anymore.

WOLLEGA UNIVERSITY in NEKEMTE

In Nekemte we had a meeting with the academic vice president of the Wollega University, Mr. Eshetu Kebede. We explained to him about podoconiosis and left some information. He seemed to be happy with our information and was willing to organise workshops on the subject for health students, biology students etc.

Later on Cora had a telephone call with the president, Professor Fekadu Beyene who was also very interested in our experience on podoconiosis. He suggested to keep in contact for further discussions of how the University can help to prevent the disease.

Wollega University in Nekemte is cooperating with Utrecht University in The Netherlands. They have an exchange program for students. Also Dutch students go there for few months to see a developing country.

ADDIS ABABA

In Addis Ababa we had an appointment at the IOCC (International Orthodox Christian Charities) office with Tsige Amberbir Research Podo manager, Mr. Teklesiasie Gelan, Inclusion of PWD Program Officer IOCC (shoe distribution), Dejene Assefa, for Toms Shoes and Christel Ahrens (nurse, midwife, missionary). Unfortunately Mr Assefa did not show up, although he called a few times that he would arrive soon.....(?)

Christel Ahrens told about her plans to start a NGO for podoconiosis, linked to the Ethiopian Evangelical Church Mekane Yesus. She plans a podo center for ca 1000 patients in Chalia in

collaboration with the government. She wants to focus on secondary prevention by having patients in a training program for 1 yr (for the worst cases 2 yrs). After that period patients have to continue their treatment on their own.

The main subject of the meeting turned out to be the **Toms Shoes program**. We all agreed that shoes are essential to prevent the disease. The Toms Shoes project can help to prevent. But not in the way the project is performing at this moment. The supply of these plastic shoes is a disaster: wet feet, fungal infections, rubbing of dirty soil into these wet feet. (Christel said that leather shoes made by a local Ethiopian factory must be possible for ca 5 dollar.) Moreover these white plastic shoes might increase the stigma for children from affected families. There might also be a cultural problem with wearing shoes: a person with shoes is seen as lazy, not strong. Another problem might be the rainy season; in this season other shoes (boots?) might be necessary.

Conclusion and advice for the Toms Shoes company is to start with more research: to find out what are the cultural inhibitions to wear shoes and how does the rainy season influence the behavior of wearing shoes? Then there should be education: teachers, health workers (for measuring feet also), parents and the last stage could be the distribution of shoes of good quality.

Christel suggested to try to get the Ethiopian Orthodox Church as a mediator for a (shoe) program.



The shoe that is distributed by Toms Shoe

Ministry of Health

At the Ministry of Health we had a meeting with Mr Rik Nagelkerke, a Canadian-Dutchman, former MSF-worker, now manager on development of health centers, who brought us in contact with a public health specialist (who knew Gail Davey as her teacher at university) who gave us the name of dr. Tizita Hailu, director pastoralist health promotion and disease prevention directorate FHOH Ethiopia. she was not there at the moment. we will email her later.

Rik Nagelkerke might have a direct contact to the minister of health. He is happy to be a mediator if we need the minister to push a program. He suggested us to give data (numbers are important, potential cases extrapolated, based on data in a smaller area), a solution for the problem, a program which the minister can promote etc. If it comes we should also stress that the problem is not insurmountable.

(governmental levels in Ethiopia are: federal- regional(Oromia)- zonal(Wollega)- worrada)

CONCLUSIONS, recommendations, future plans.

We can cite our last report: “podoconiosis is a disease, which is strongly related to poverty, bare foot walking and lack of water. However education, cleaning of the feet, wearing shoes and intensive treatment can improve the situation of the patients and can make a lot of difference in their lives and prevent their children from getting podoconiosis”. But still there is a lot to do in the programs: not all patients are as good as they could be: a well-organized program with more good education, good access to water, but also free supply of treatment materials and shoes can contribute to the improvement of affected patients. It might be good to make a step by step program: how to start a podoconiosis program in a new clinic (see literature? Gail Davey ao). Also the current programs might benefit from having workshops for all health workers about podoconiosis.

Other wishes are: less use of antibiotics, banning of plastic shoes. This also implies that the current Toms Shoes program should be altered into a more well-thought-out program. We will write a letter (together with others involved) to Toms Shoes.

There might be an option for bandaging, especially for patients with soft edema. Finding good bandages is a problem in Ethiopia. We still have to try to take samples to show which ones are ideal or try to find “African” bandages (strips of sheets, nettala’s?). We will try to find out if there is a possibility for a kind of universal stockings.

Big nodules are a problem for fitting into shoes. Shoes bigger than size 45 are necessary. Then the shoemakers will need to be supplied with bigger soles. We have to find out if bigger soles exist in Ethiopia or if they can be produced.

For very selected patients surgical nodulectomy is an option. For the big debulking operation there is no place anymore.

No doubt that there are many more patients, inside and outside the catchment areas of the clinics and hospitals, who are still not aware of the possibilities to make their legs and their life better. Also outside the clinics there is work to do in educating health workers, teachers and the public. Our contact with Wollega University might be a possibility to further educate health workers and spreading the information.

We will continue to have contact with the Ministry of Health and will start email contact with Tizita Hailu at the Ministry. We will continue our contacts with other groups in and outside Ethiopia who are also active with podoconiosis.

The new WHO page on podoconiosis (see attachment 1) has two suggestions which may be useful for the programs in the future. To prevent contact with irritant soil: covering floor surfaces inside traditional huts and training treated patients in skills that enable them to generate income without contact with irritant soil.

Intentions to do in the Netherlands

We want to make business cards and a short introduction brochure in English with some pictures (see Wollayta brochure)

We want to write short articles in Medisch Contact, Amice and the Lymphoedeem periodical.

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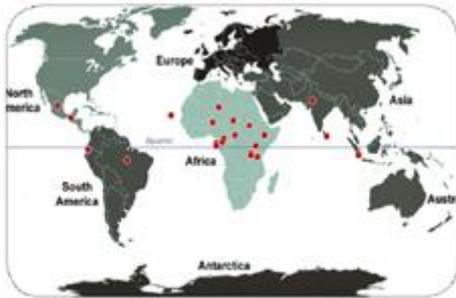
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Podoconiosis: endemic non-filarial elephantiasis



Podoconiosis is a type of tropical lymphoedema clinically distinguished from lymphatic filariasis (LF) through being ascending and commonly bilateral but asymmetric. Evidence suggests that podoconiosis is the result of a genetically determined abnormal inflammatory reaction to mineral particles in irritant red clay soils derived from volcanic deposits.

Distribution

Podoconiosis is found in highland areas of tropical Africa, Central America and north-west India. See map: Global distribution of podoconiosis (from Nenoff et al., 2009)*.

Disease burden

Population-based surveys suggest a prevalence of 5–10% in barefoot populations living on irritant soil. In Ethiopia, 1 million people are estimated to be affected, while in Cameroon, a further 500 000 people are estimated to be affected. The economic consequences are severe: productivity losses per patient amount to 45% of working days per year, thus economic losses to a country such as Ethiopia exceed US\$ 200 million per year. Stigmatization of people with podoconiosis is pronounced; patients being excluded from school, local meetings, churches and mosques, and barred from marriage with unaffected individuals.

Who is affected?

Men and women are equally affected in most communities. All of the major community-based studies have shown onset of symptoms in the first or second decade and a progressive increase in podoconiosis prevalence up to the sixth decade. Farmers who for cultural reasons or through sheer poverty do not wear shoes are at high risk, but the risk extends to any occupation with prolonged contact with the soil.

Pathology

Podoconiosis is characterized by a prodromal phase before elephantiasis sets in. Early symptoms commonly include itching of the skin of the forefoot and a burning sensation in the foot and lower leg. Early changes that may be observed are splaying of the forefoot, plantar oedema with lymph ooze, increased skin markings, hyperkeratosis with the formation of moss-like papillomata (left) and rigid toes. Later, the swelling may be one of two types: soft and fluid, or hard and fibrotic, often associated with multiple hard skin nodules. Acute adenolymphangitis episodes occur in which the patient becomes pyrexial and the limb warm and painful. These episodes appear to be related to progression to the hard, fibrotic leg.

Diagnosis

Diagnosis is based on location, history, clinical findings and absence of microfilaria or antigen on immunological card test. Podoconiosis occurs in populations living at high altitudes (more than 1000 metres above sea level).

Disease starts in the foot and progresses up the leg to the knee but rarely involves the groin; conversely, LF is found at lower altitudes and changes often are noticed first in the groin.

Prevention and management

Primary prevention consists of avoiding or minimizing exposure to irritant soils by wearing shoes or boots and by covering floor surfaces inside traditional huts.

Secondary prevention involves training in a simple lymphoedema treatment regimen, similar to that used in management of LF lymphoedema. The regimen includes daily foot-washing with soap, water and antiseptic, use of a simple emollient, bandaging in selected patients, elevation of the leg, controlled exercises, and use of socks and shoes. Compression bandaging is highly effective in reducing the size of the soft type of swelling (patient shown before [left] and after [right] 6 months of treatment).

Tertiary prevention encompasses secondary prevention measures, elevation and compression of the affected leg, and, in selected cases, removal of prominent nodules. More radical surgery is no longer recommended since patients unable to scrupulously avoid contact with soil experience recurrent swelling which is more painful than the original disease because of scarring. Social rehabilitation is vital, and includes training treated patients in skills that enable them to generate income without contact with irritant soil.

* Nenoff P et al. Die Podokoniose als nicht-filariöse, geochemisch bedingte Elephantiasis - eine vergessene tropische Erkrankung? [Podoconiosis as a non-filarious, geo-chemically induced elephantiasis – a forgotten tropical disease?]. *Journal der Deutschen Dermatologischen Gesellschaft*, 2009, 1–7.

attachment 2

Skin snip test: useless

Misunderstanding in testing

We found it confusing that still some clinics do tests with which they “diagnose” lymphatic filariasis. They use 2 tests: a provocation test with diethylcarbamazine (DEC) and a skin snip test.

Both tests are diagnosing onchocerciasis (*O.volvulus*) and not lymphatic filariasis (*Wuchereria Bancrofti*).

A short explanation to settle this business: Onchocerciasis and lymphatic filariasis are both diseases caused by filariae (nematodes or roundworms).

Onchocerciasis is spread by a blackfly. The clinical signs are in the skin and in the eyes: itching, depigmentation (leopard skin) and keratitis, eventually causing blindness in the long run. Diagnosis is made by

showing microfilariae in *a piece of skin* under the microscope or by the Mazzotti test: giving a single oral dose of 50 microgram DEC, which causes intense itching after 20-90 minutes in oncho-infected patients. Onchocerciasis is widespread in the Wollega area and is treated by a mass treatment program, annually provided by the government. This medication does not kill the adult worms, just kills the microfilaria, produced by the worm. So after treatment, levels of microfilariae can reaccumulate over many months (and show up in the skin snip) and treatment has to be repeated.

Lymphatic filariasis is spread by a mosquito and does not exist in high altitudes as in the Dembidollo and

Nekemte area. (This might change in the future with the climate changes) Clinical signs are lymphoedema of the whole 4 limbs, genitalia and breasts (and not just the lower legs as in podoconiosis) Diagnosis is made by *blood tests* only and **not** by a skin test.

This means that: by doing a skin snip test you are testing on onchocerciasis!! A positive skin snip test (seeing microfilaria) means that this is an onchocerciasis patient.