

FEDERAL DEMOCRATIC REPUBLIC OF ETHIOPIA MINISTRY OF HEALTH

LYMPHATIC FILARIASIS AND PODOCONIOSIS MORBIDITY MANAGEMENT AND DISABLITY PREVENTION GUIDELINES

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Foreword

n 2013, Ethiopia identified eight priority Neglected Tropical Diseases (NTDs) with the aim of eliminating and reducing the impact of these diseases by 2020. Lymphatic filariasis (LF) and podoconiosis are two of these diseases. Countrywide integrated mapping of LF and podoconiosis has been undertaken by the Federal Ministry of Health (FMOH) in 2013. The integrated mapping of these two diseases have identified 70 LF and 345 podoconiosis endemic districts all over the country. In total 35 million and 5.7 million people are at risk of podoconiosis and LF in the country respectively. These estimates enabled the scaling up of preventive interventions to the at risk population.

These two diseases cause severe morbidity and disability among a considerable proportion of affected individuals. Therefore, morbidity management and disability prevention (MMDP) for affected individuals is an important component of the elimination of these two diseases. The goal of MMDP is not only to treat clinical symptoms but to prevent further medical, psychological, economical and social complications caused by the diseases. This is achieved by ensuring that people with disabilities have equal access to quality health, education, livelihood and community services, including surgery and self-help training.

The MMDP guideline provides practical guidance on patient management and disability prevention based on practical in-country field experiences. The guideline is enriched by contributions from experts in the field. It provides guidance on planning, implementation and monitoring morbidity management and disability prevention activities. It also provides the best available information on managing morbidity and preventing disability after acute dermatolymphangioadenitis (ADLA; acute attacks), lymphedema or elephantiasis, and hydrocele.

To achieve the elimination target and morbidity reduction goals the guideline will be made available to all health professionals and program managers working in endemic areas in Ethiopia.

The Federal Ministry of Health appreciates the contribution from individuals and partners in the development of this guideline. We believe these concerted partnerships will continue in the dissemination and rollout of the implementation of the guideline. FMoH therefore calls all stakeholders to collaborate and strengthen our efforts to improve the quality of life and end the suffering of those affected.

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1 ACRONYMS

ADLA Acute Dermatolymphangioadenitis/ Adenolymphangitis

BCC Behavior Change Communication

FMOH Federal Ministry of Health

GPELF Global Programme to Eliminate Lymphatic Filariasis

HDA Health Development Army
HEW Health Extension Workers

HMIS Health Management Information System

ICF International classification of functioning disability and health

IEC Information, Education and Communication

Kg Kilogram

LF Lymphatic filariasis

MDA Mass Drug Administration

mm Millimeter mg Milligram

MMDP Morbidity Management and Disability Prevention

NTD Neglected Tropical Diseases
PHCU Primary Health Care Unit

Podo Podoconiosis

RHBs Regional Health Bureaus

SNNP Southern Nations and Nationalities People

TWG Technical Working Group

USD United States Dollar

WHO World Health Organization

WHODAS World Health Organization Disability Assessment Schedule

WHOQOL World Health Organization Quality of Life

μg Microgram

2 GLOSSARY

Acute attack Also known as adenolymphangitis refers to the sudden onset of fever and

localized pain and warmth, with or without swelling or redness in the limb or

other affected parts of the body.

Adenopathy Also referred to as lymphadenopathy, is the enlargement of lymph nodes

anywhere in the body.

Ankylosis Immobility and consolidation of a joint.

Antigenemia The presence of antigen in the bloodstream.

Chyle Fat-laden white lymph mostly returning from the lymphatics of the intestine.

Chyluria A condition of passing white coloured urine due to an influx of accumulated

lymph from engorged lymphatic vessels of the urinary system.

Chyloascites Accumulation of chyle in the abdominal cavity.

Chylocele An effusion of chyle into the tunica vaginalis propria and space of the tunica

vaginalis testis.

Chylothorax A rare condition that results from thoracic duct damage with chyle leakage

from the lymphatic system into the pleural space.

Disability Inability to adequately or independently perform routine daily activities such as

walking, bathing and toileting; the negative aspects of the interaction between a person with a health condition and her or his context (environmental and

personal factors).

Elimination of LF A state of bringing the microfilariae rate to below one percent in blood samples

examined. In such a low microfilaraemic state, LF ceases to be a public health

problem due to gradual decline of transmission.

Elephantiasis An advanced stage of a grossly enlarged affected part with non-pitting oedema,

thickened papillomous skin often bearing nodules and warty growths on the

surface.

Endosymbionts These are organisms living together within other organisms enjoying mutual

support. In the context of this manuscript, the symbiont is a bacterium.

Eosinophilia A condition of increased eosinophils in the blood.

Epididymitis Inflammation of epididymis, one of the genital organs of a male.

Filariasis A common term for a group of parasitic diseases called nematodes. Filariasis

caused by nematodes mostly living in the lymphatic system is called lymphatic

filariasis or LF.

Fissure A groove, natural division, deep furrow, elongated cleft, or tears in various

parts of the body.

Geographical coverage Proportion of administrative units in which morbidity management and

disability prevention activities are being implemented out of all those that

require such activities.

Haematuria Blood in the urine.

Haematocele Blood in the scrotal sac.

Hydrocele Accumulation of a straw-coloured fluid in the tunica vaginalis, a sac in which

the testis rests.

Hydrocelectomy An operation for hydrocele.

Hyperkeratosis Thickening of the outer layer of skin.

Larvae An organism in an early stage of development that differs greatly in appearance

from its adult.

Lymphocele A collection of lymphatic fluid within the body not bordered by epithelial

lining.

Lymphadenitis Inflammation of the lymph glands.

Lymphadenopathy A condition of enlargement of the lymph glands.

Lymphangitis Inflammation of lymph vessels.

Lymphoedema A chronic progressive swelling of one or more parts of the body due to

accumulation of fluid, which is gradually replaced by fibrous tissue and

hardening of swelling.

Lymph stasis A condition where the circulation of the lymph fluid slows down.

Mortality Death due to a disease or other conditions.

Morbidity Suffering due to a disease or other conditions.

Nematodes A group of organisms having unsegmented, cylindrical bodies, often

narrowing at each ends, and including parasitic forms such as filarial worms.

Microfilariae Microscopic baby forms of filarial worms.

Occult filariasis A condition in which the classical manifestations of filariasis are absent.

Microfilariae are not present in the blood, but present in other tissues such as

the lung. Tropical eosinophilia is such a condition.

Oedema Swelling of any part of the body due to an accumulation of fluid in the tissue.

Orchitis Inflammation of the testis.

Papillomatosis A condition in which the skin surface shows minute warty growths on the

surface.

Paronychia Nail infection.

Pyocele Pus in the scrotal sac.

Vector An agent, such as a mosquito, that carries disease-causing microorganisms

from one host to another.

3 INTRODUCTION

he World Health Organization (WHO) has identified seventeen neglected tropical diseases (NTDs) for control and elimination at the global level[1]. Among these diseases, eight are identified as priority NTDs in Ethiopia with a range of endemicity across the regions and districts[2].

Cognizant of the burden of these diseases and their damaging effect on the overall socioeconomic development of the country and the wellbeing of the people, the Ethiopian government has launched the first National Master Plan for Neglected Tropical Diseases in 2013[2]. Hence forth, lymphedema, caused both by lymphatic filariasis and podoconiosis, have been brought forward amongst the priority Neglected Tropical Diseases (NTD) for control and ultimately, elimination.

Nearly, 70 districts in six regional states (Amhara, Oromia, Benishangul-Gumuz, Southern Nations and Nationalities People (SNNP), Gambella and Tigray) are endemic for lymphatic filariasis leaving an estimated 5.7 million people at risk of infection[3]. To interrupt transmission and ultimately eliminate LF, mass drug administration (MDA) using a combination of two drugs - Albendazole and Ivermectin - to treat the entire populations at risk has been undertaken in 65 districts starting 2009. In addition, vector control with long-lasting insecticide treated nets and an indoor residual spraying campaign are integrated with the malaria control program as Anopheles mosquitoes are the main LF vector in Ethiopia. It is envisaged that this intervention would enable Ethiopia to contribute its share in achieving the Global Programme to Eliminate Lymphatic Filariasis (GPELF) targets for interrupting transmission by 2020.

Likewise, close to 35 million people in the country live in 345 districts endemic for podoconiosis[4]. Working with development partners, efforts are exerted in some endemic woredas at preventing new disease and improving morbidity management and disability prevention through enhancing the behavior of wearing protective shoes and/or washing the dust off the affected limbs using soap and water. In this regard, it was possible to reach over 60,000 podoconiosis patients in over 40 districts in Amhara, Oromia and SNNP Regional States.

Nonetheless, lymphedema remains the most common clinical consequence for both LF and podoconiosis while hydrocele is common amongst male LF patients. Stigmatization and discrimination of people with elephantiasis is also pronounced with patients being excluded from school, social and religious functions, further leading to marginalization and intergenerational poverty. With severe economic consequences, productivity losses per patient and economic losses to the country is huge; for podoconiosis only, this is estimated to exceed USD200 million per year.

These Lymphatic Filariasis and Podoconiosis Morbidity Management and Disability Prevention Guidelines are aimed at standardizing the management of lymphedema, adenolymphangitis (acute attacks due to lymphedema) and hydrocele. It also guides how health workers can help those patients encountering additional psychological and socioeconomic problems. The guidelines are primarily informed by the Lymphatic filariasis: managing morbidity and preventing disability: an aide-mémoire for national programme managers published by the WHO Global Programme to Eliminate Lymphatic filariasis and studies and publications on podoconiosis.

It is envisaged that general medical practitioners, health officers, nurses and other mid-level health practitioners and social workers would find the guidelines helpful in their efforts to alleviating morbidity and disability resulting from LF and podoconiosis.

4 MORBIDITY MANAGEMENT AND DISABILITY PREVENTION (MMDP)

A

significant proportion of the public health problems represented by lymphatic filariasis and podoconiosis are due to impairment and disability related to lymphedema and hydrocele (LF only). Although these clinical manifestations are not often fatal, they are the leading causes of permanent and long-term disability. Therefore, national programs must focus on managing morbidity and preventing disability caused by these conditions.

MMDP must be continued in endemic communities after mass drug administration for lymphatic filariasis has stopped and after surveillance and validation of interruption of transmission, as chronically affected patients are likely to remain in these communities. Furthermore, MMDP should be integrated into the primary health care system to ensure sustainability.

Management of morbidity and disability require a broad strategy involving both secondary and tertiary prevention. Secondary prevention includes simple hygiene measures, such as basic skin care, to prevent acute attacks and progression of lymphedema. For management of hydrocele, surgery may be appropriate. Tertiary prevention includes psychological and socioeconomic support for people with disabling conditions to ensure that they have equal access to rehabilitation services and opportunities for health, education and income.

The public health priorities in terms of disability due to lymphatic filariasis and podoconiosis are lymphedema and hydrocele (LF only), the main manifestations of the diseases. Management of other clinical forms, such as chyluria, lymphocele, scrotal lymphedema, tropical pulmonary eosinophilia, adenopathy and hematuria, should follow standard clinical and referral practices, as public health approaches have not yet been established.

Lymphedema or its more advanced form, elephantiasis (primarily of a lower limb) can be managed by hygiene and skin care to prevent acute attacks, proper wound care, exercise, elevation of the affected limb and proper footwear.

These simple measures are essential because they:

- are effective in reducing the number of acute attacks;
- improve the quality of life of patients;
- can be maintained for several years by home-based care.

Hydrocele, one of the urogenital conditions related to lymphatic filariasis, is effectively cured by surgery, and this has been shown to improve mens' economic situation, community participation and quality of life.

To prevent disability, people with disease related to lymphatic filariasis or podoconiosis should also have access to psychological and social support to assist their reintegration into society and economic life.

Activities beyond medical care and rehabilitation include promoting positive attitudes towards people with disabilities, preventing the causes of disabilities, providing education and training, supporting local

initiatives, and supporting micro- and macro-income-generating schemes. The activities can also include education of families and communities, to help patients to fulfill their roles in society. Thus, vocational training and appropriate psychological support may be necessary for overcoming the depression and economic loss associated with the disease.

4.1 Goal and Objectives of MMDP

The goal of MMDP is to alleviate suffering in people with lymphedema and/or hydrocele thereby improving their quality of life.

The general objective is to provide the recommended essential care for every person with these manifestations in all areas where lymphatic filariasis and/or podoconiosis is endemic.

The specific objectives of MMDP are to achieve:

- Full geographical coverage of MMDP services in all lymphatic filariasis and/or podoconiosis endemic areas;
- Availability of recommended essential care for people with lymphedema and/or hydrocele in areas where lymphatic filariasis and/or podoconiosis is endemic; and
- A reduction in the frequency and intensity of acute attacks for people with lymphedema.

Success in achieving these aims can be measured by:

- Estimated number of patients with lymphedema and/or hydrocele by woreda;
- Number of designated facilities with lymphedema or hydrocele services by woreda; and
- Percentage of designated facilities providing lymphedema or hydrocele services that have been assessed for quality of care.

Information on these three indicators is requested by WHO to be included in the national program's dossier on the elimination of LF as a public health problem.

4.2 Policy and Guiding Principles

The aim of MMDP at all levels is to give every patient with lymphedema and/or hydrocele a better, more productive life and allow them to participate equally in the community; both socially and economically. By 2020, the national program should have achieved full geographical coverage of essential recommended care in all endemic areas for lymphatic filariasis and/or podoconiosis.

The guiding principles and policies for MMDP are:

- A. **Availability:** provide availability of essential care for all patients with lymphedema and/or hydrocele.
- B. **Flexibility:** allow flexible approaches to strategies for preventing and alleviating disabilities.
- C. **Integration:** whenever possible, integrate the activities into other disease control programs.
- D. **Quality of Care:** provide care that meets quality standards of effectiveness, efficiency, accessibility, acceptability, equity, and safety.
- E. **Continuity of Care:** provide access to continuing care to lymphedema patients throughout their lives, both to manage the disease and to prevent progression to more advanced stages.

5 LYMPHATIC FILARIASIS

ymphatic filariasis (LF) is a chronic infectious disease with almost 120 million people infected worldwide[5] and around 5.7 million people at risk of infection in Ethiopia[3]. It is stated to be the second leading cause of long term disability and socioeconomic consequences in the world, causing severe disabilities and socioeconomic problems over the course of a life time. LF has been identified as one of the neglected tropical diseases with high potential for elimination, due to better understanding of various factors and the availability of new tools. Disability alleviation continues to be a priority in the country and there is immediate need to strengthen the morbidity management[5].

5.1 Agent and Transmission of the Disease

LF in Ethiopia is caused by the filarial nematode <u>Wuchereria bancrofti</u> and is transmitted by Anopheles mosquitos. Female mosquitoes are infected with the microfilariae during their blood meal. These microfilariae develop within the mosquito's body through four stages and change into infective larvae within 2–3 weeks. The mosquitoes infect a person during the next blood meal. These larvae become male and female adult worms within a period of 8–12 months and starts producing microfilaria and continue the cycle. The adult worms live for a period of 5–8 years (Figure 1).

Recently, an endosymbiont named Wolbachia, was demonstrated to be present in all stages of the parasite. This bacterium is found to be responsible for growth, viability and fertility of the parasites and is involved in inflammatory reactions.

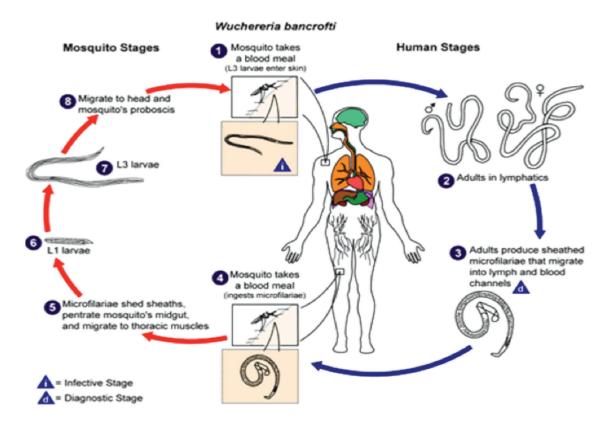


Fig.1. Life cycle of Wuchereria bancrofti

5.2 Socio-economic impact

Lymphedema and hydrocele due to LF can lead to permanent, long-term disability; they also often cause disfigurement, with serious psychosocial and economic consequences. Although there are no studies conducted in Ethiopia to evaluate the economic burden of LF, studies in other countries suggested the cost to patients of treating ADLA episodes ranges from USD 0.25 to 1.62, almost 2 days' wages in some countries, while the cost of hydrocoele surgery, depending on the country and source of care, is USD 5–60[6]. ADLA was estimated to be responsible for losses of USD 60–85 million per year in India[7] and USD 38 million per year in the Philippines[8]. Furthermore, disability and disfigurement due to chronic manifestations often means that patients have to stop working or change to less productive jobs. Lymphatic filariasis also exerts a heavy social burden on patients, as chronic complications are often considered shameful and prevent patients from playing their role in the society and from leading a fulfilling emotional life.

5.3 Disease Manifestations

Lymphatic filariasis has a wide spectrum of clinical manifestations starting from a few non-specific symptoms to highly debilitating disabilities. Broadly, it has chronic and acute manifestations.

5.3.1 Chronic manifestations

Chronic manifestations of LF include both lymphedema and hydrocele. Lymphedema arises as a result of an obstruction to the lymph flow, leading to an accumulation of fluid (edema). The severity of the lymphedema can be graded for non-research purposes into three grades. In the initial period, the edema is pitting on finger pressure and subsides on elevation of the affected part. This condition is known as lymphedema (grade I). The parts of the body affected can be feet, hands, breasts, scrotum and other genitalia of both sexes. Subsequently, the swelling becomes non-pitting, and remains irreversible on elevation (grade II). Gradually the overlying skin becomes thickened; rough, hard and folded (grade III). In the advanced stage, the creases of skin folds become deeper and invisible; and in some cases external growths such as knobs and warty growths are observed. Such a large disfigured state of the limb is called elephantiasis.

Hydrocele is a chronic condition affecting males in which there is excessive collection of a straw-coloured fluid in the two-layer sac which surrounds the testis and epididymis. The scrotum enlarges to various sizes, in some cases obliterating the entire penis. The overlying skin can also become thickened and hard with accompanying problems of lymphedema.





Fig. 2 Clinical manifestation of filariasis: Bilateral filarial hydrocele and filarial elephantiasis showing nodular and verrucous changes of the skin

5.3.2 Acute manifestations

Acute attacks, also known as ADLA, refer to the sudden onset of fever and localized pain and warmth, with or without swelling or redness in the limb or other affected parts of the body. They can happen when adult worms die, when there are bursts of microfilariae, or when secondary bacterial and fungal infections occur. The main symptoms of acute attacks can include:

- Swollen lymph nodes (swelling in groins and axillae due to lymphadenitis)
- Increased swelling in affected limb/body part and warmth in that limb/body part
- Pain
- Redness of the skin
- Feelings of fever

These acute attacks commonly last one week and generally manifest within six months to one year after infection. During an attack, the LF sufferer may not be able to walk or to get out of bed. The limb or other affected part of the body is extremely painful and even the lightest touch can be unbearable. Skin exfoliation of the affected body part usually occurs with the resolution of an episode. Recurrent acute attacks cause constant sufferings to the patient and simultaneously worsen the size and complications associated with the lymphedema thus making their prevention crucial. Awareness-building on prevention and cleaning of entry lesions is required among health providers and persons affected with lymphedema to prevent recurrent acute attacks.



Fig.3: clinical manifestation – Acute Attack

5.4 Differential Diagnosis

A diagnosis of elephantiasis is made based upon a thorough clinical evaluation, a detailed patient history and identification of characteristic symptoms. Symptoms of the following disorders can be similar to those of elephantiasis. Hence, comparisons may be useful for a differential diagnosis.

- **A. Podoconiosis** is clinically distinguished from LF through being ascending and commonly bilateral but asymmetric[9].
- **B. Lymph stasis** results in the accumulation of lymph. Problems due to abnormal lymphatics are rupture of dilated lymphatics resulting in chyluria, lymph scrotum, chylocele, chyloascites and chylothorax.
- **C. Genital elephantiasis** can also be caused by bacterial sexually transmitted infections, specifically lymphogranuloma venereum (LGV) and donovanosis. The bacterium that results in LGV, Chlamydia trachomatis serovar L1-L3, damages the lymphatic system resulting in lymphatic obstruction in the genitals. Chronic obstruction eventually results in genital elephantiasis. Donovanosis caused by the bacterium Calymmatobacterium (Klebsiella) granulomatosis, causes genital elephantiasis because the body's immune system response to the bacterium causes inflammation and narrowing (constriction) of the lymphatic vessels[10].
- **D. Hereditary lymphedema**, also known as primary lymphedema, is a genetic developmental disorder affecting the lymphatic system. It is characterized by swelling (edema) of certain parts of the body. Lymphatic fluid collects in the subcutaneous tissues under the epidermis due to obstruction, malformation, or underdevelopment (hypoplasia) of various lymphatic vessels. Symptoms include swelling (lymphedema) and thickening and hardening of the skin in affected areas[11].

- **E. Epididymal cyst** is a painless, fluid-filled cyst in the long, tightly coiled tube that lies above and behind each testicle (epididymis). The fluid in the cyst may contain sperm that are no longer alive. It feels like a smooth, firm lump in the scrotum on top of the testicle. These cysts may grow to larger cysts called spermatocele. It is usually diagnosed by shining a light behind each testicle (transillumination) while light will not pass through solid masses that may be caused by other problems[12,13].
- **F. Lymphoma,** a form of cancer that affects the lymphatic system, is characterized by the formation of solid tumors in the immune system. Usually the enlargement of lymph nodes does not go away (as it does after infection)[14].
- **G. Lymphadenitis,** the inflammation of a lymph node (lymph glands), is often in response to bacterial, viral, or fungal infection. The swollen glands are usually found near the site of an infection, tumor, or inflammation. It is sometimes accompanied by lymphangitis, which is the inflammation of the lymphatic vessels that connect the lymph nodes. Lymphadenitis is marked by swollen lymph nodes that are red and tender. If the lymphatic vessels are also infected, there will be red streaks extending from the wound in the direction of the lymph nodes[15].
- **H. Other rare causes of elephantiasis** include leishmaniasis, tuberculosis, leprosy, and a repeated streptococcal infection. Elephantiasis may also occur secondary to trauma, surgery or radiation. For example, treatment such as the surgical removal of lymph nodes to treat cancer may result in the accumulation of lymph and subsequent swelling (lymphedema).

5.5 Diagnosis

The key method of identifying LF patients is clinical identification/diagnosis based on the signs and symptoms as mentioned above. History of residence in a known LF-endemic area is also useful to confirm a case. In non-routine cases, microscopy or antigen tests could be helpful in diagnosing cases of lymphedema caused by LF. However, patients that have lymphedema or hydrocele caused by LF are often not positive for microfilariae or antigenemia.

See management section for further details on differential diagnoses and what defines a complicated case.

5.6 Control and Prevention of LF

The prevention methods are aimed at reducing transmission of the disease through reducing human contact with mosquitoes and reducing the amount of microfilariae circulating in the human population. Vector control can include use of insecticide-treated nets or indoor residual spraying campaigns. Mass drug administration with Albendazole and Ivermectin is targeted at all people living in endemic areas in order to kill circulating microfilariae in infected people's blood thereby interrupting the transmission of the disease.

6 PODOCONIOSIS

6.1 Agent and Diseases Occurrence

odoconiosis, also called endemic non-filarial elephantiasis, is a non-communicable disease that is acquired through prolonged exposure to red clay soils of volcanic origins. Mineral particles from the soil penetrate the skin and are taken up by macrophages in the lymphatic system which causes inflammation and fibrosis of the vessel lumen leading to blockage of the lymphatic drainage. The disease occurs primarily where red clay soils are found in areas of high altitude (over 1000m), with high seasonal rainfall (over 1000mm per year).

The exact global burden is still to be measured, but it is estimated that at least 6 million people are affected worldwide, of which 3 million are in Ethiopia. Podoconiosis has been described in more than ten countries across tropical Africa, and has also been reported in tropical areas of Central America and Southeast Asia.

The disease typically manifests itself between the ages of 10 and 30. In addition, genetic studies have shown genetic susceptibility in certain families to podoconiosis. Podoconiosis is typically observed in rural subsistence farmers whose trade, culture, and economic circumstances often make it uncomfortable, against cultural norms, or a financial burden to wear shoes.

6.2 Socio-economic Impact

In addition to the health impact, podoconiosis has severe social and economic consequences. According to a study in southern Ethiopia, the annual economic cost of podoconiosis was more than 200 million USD per annum for the country. People with podoconiosis were found to be half as productive as those without podoconiosis given they are working the same jobs, and lose 45% of their economically productive time because of morbidity associated with the disease. Total direct costs of podoconiosis amounted to the equivalent of USD 143 per patient per year[16]. Social stigma against people with podoconiosis isrife and includes patients being excluded from school, denied participation in local meetings, churches and mosques, and excluded from marriage with unaffected individuals.

6.3 Disease Manifestations

Early symptoms of podoconiosis include a burning sensation in the leg, itching, and knocking of the big toes whilst walking. The key early signs of podoconiosis are splaying of the forefoot, transient plantar and lower leg edema that disappears after overnight rest, thickening of the skin over the anterior and posterior dorsum of the foot, and rough, warty and papilomatous growths that look like a "moss" on the anterior one-third and sole of the foot. With time, the swelling becomes soft and pitting ('water-bag type') or nodular and fibrotic ('leathery type'). Late stage disease is characterized by fusion of the inter-digital spaces and ankylosis of the inter-pharyngeal and ankle joints (Annex 7).

A common clinical presentation and a frequent cause of morbidity in podoconiosis Adenolymphangitis also called acute attacks - characterized by recurrent infection resulting from compromised immunologic clearance in the lymph edematous limb. Acute attacks manifest as reddened, hot, and tender limbs combined with fever and chills.

6.4 Differential diagnosis

When diagnosing and treating podoconiosis, there are several other diseases causing swollen legs that must be considered: Filarial lymphedema (LF), leprosy, onchocerciasis; rheumatic heart disease, post-surgery and Milroy's disease. The first three are the most common alternative diagnoses in Ethiopia, and will be dealt with in more depth here.

The swelling of podoconiosis usually starts from the lower leg with burning sensation and upward progressive swelling to the level of the knees. Not only is the causal agent of podoconiosis different from that of LF (the common cause of lymphedema), but it also differs in several other ways. LF is the first alternative diagnosis to consider. Two questions help decide whether the patient has podoconiosis or LF: Where did the swelling start? The swelling of podoconiosis starts in the feet and proceeds up the leg; that of LF starts at the groin and proceeds down the leg.

Leprosy is frequently found in podoconiosis areas, and one of the consequences of long-term leprosy infection may be leg or foot swelling. The most important way of distinguishing the two conditions is to test for sensation in the foot. The leprosy disease process causes decreased sensation in addition to swelling, whereas in podoconiosis, sensation remains intact. If examination for skin depigmentation and thickened nerves suggests leprosy, the patient must be referred for anti-leprotic therapy.

Onchocerciasis (river blindness) may sometimes be found in areas in which podoconiosis is also endemic. Skin changes (itchy skin rash and 1-2cm nodules or bumps) on the trunk and arms are common in onchocerciasis. In some countries, eye changes are common in onchocerciasis, but these changes are rare in Ethiopia. Patients suspected to have onchocerciasis must be referred on.

6.5 Diagnosis

Podoconiosis is a clinical diagnosis based on exclusion of other causes of lymphedema. The current diagnosis is based on history, physical examination and some disease-specific tests to exclude common differential diagnosis. Some studies have clearly indicated that in endemic districts, trained health workers can identify the cases using clinical diagnosis.

6.6 Control and Prevention of Podoconiosis

The prevention methods are aimed at preventing the prolonged contact between barefoot and irritant volcanic soils. Passage of the trigger through the skin of the feet can be prevented using the following simple measures:

- Proper and regular use of footwear;
- Daily foot washing;
- Replacing earth floors with concrete or covering floors.

7 ESTIMATING THE NUMBER OF PATIENTS

stimating and mapping the number of people with lymphedema and hydrocele is important for targeting interventions, prioritization and monitoring progress. If the number of people affected per woreda (district) or kebele is known, those with high burden districts or kebeles will be targeted and given priority for interventions. In Ethiopia, mapping of podoconiosis and LF has been conducted at national level. The prevalence data at woreda level were used to identify areas requiring intervention. Although estimation of the number of case using this data is possible, rapid assessment and registration of lymphedema and hydrocele cases by the health development army (HDA) and health extension workers (HEW) is important to estimate the exact number of cases and their geographical distribution within the woreda (Figure 4). In addition to understanding the number of cases, listing of the cases will be helpful for the purposes of planning.

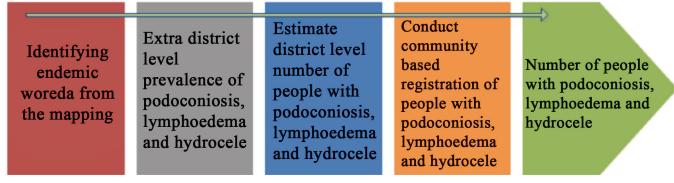


Fig.4 Framework for estimating people with podoconiosis, lymphedema and hydrocele

7.1 Estimating Using Mapping Survey

The national mapping survey of LF and podoconiosis was conducted to identify high risk communities for LF and podoconiosis. The mapping used a two-stage cluster convenience sampling. The primary sampling unit for the survey was the kebele (lowest level administrative structure, population approximately 5000). Two kebeles were selected from each woreda based on reported history of lymphedema cases collected through interviewing the woreda health officials and health providers one day prior to the survey. The secondary sampling unit was individuals selected within each village using systematic sampling from a random start point. Mobilization was conducted one day prior to the survey using HEWs. Every adult in the community was informed through house-to-house visits that a survey was to be conducted, and were invited to participate. On the day of the survey, all persons aged 15 years and above living in the selected communities were invited to gather at a convenient point. The study objectives were then explained in the local language, and those willing to participate were asked to form two lines, one of men and the other of women. Fifty individuals were selected from each line using systematic sampling from a random start point, resulting in an overall sample of 50 males and 50 females. Two hundred individuals were therefore tested in each woreda.

Although the exact number of people with podoconiosis, LF lymphedema and hydrocele cannot be obtained from the survey, good estimation of cases can be obtained using the survey results. The number of people with podoconiosis, LF lymphedema and hydrocele can be calculated. The estimation from the mapping will help to identify high priority districts. However, follow up case identification is required to identify the exact number of cases and their geographical distributions.

7.2 Community-Based Census

A community-based census of cases in endemic high burden woredas will be important to quantify the exact number of cases. This exercise will help the HEWs and HDAs to be familiar with the problem and to appreciate the burden in their communities. HEWs and HDAs should be trained to differentiate simple and transit swelling from lymphedema. In addition, HEWs should be able to conduct staging and grading of podoconiosis, LF lymphedema and hydrocele. Trained HEW and the HDA are well positioned in the community to register people with podoconiosis, LF lymphedema and hydrocele in the community. Important information to be collected in the community include the age, sex, kebele, type of swelling and stage of the disease for both podoconiosis, hydrocele and lymphedema due to LF. These figures can be aggregated at woreda and zonal level.

As Ethiopia moves towards 100% geographic coverage for MDA in LF endemic woredas, it is important to search for synergies wherever possible to address both MDA and morbidity needs. A prime example of this is the possibility of carrying out a lymphedema and hydrocele burden assessment together with the community registration activity which takes place before every MDA. This has the advantage of capturing all of the potential lymphedema and hydrocele cases in a community via house to house visits. Some things to consider with this strategy might be the willingness of men to reveal having hydrocele to a community health worker, especially if the community health worker is female. The ability of a community health worker to accurately identify lymphedema may also be a limiting factor.

It is important to note that a good practice for both of these strategies would be to include information on where and how to refer hydrocele cases to surgical services and basic lymphedema management techniques during the training of the HEW/HDA. In this way, population registration teams can provide basic advice to potential LF clinical cases, instead of just collecting their information.

The registration of cases can use different levels, trained HDAs can line list all the cases of lymphedema and hydrocele and trained HEW will further verify the lymphedema and hydrocele cases reported by HDAs. Health workers from health centers or woreda health offices will further conduct verifications in a sample of the cases. A previous study in Ethiopia indicated community health workers can identify lymphedema cases[17].

Whenever possible using mobile technology for the data collection is highly recommended since it improves the quality of data and avoids data entry and associated costs. Such an example could be the use of SMS text linked to a cloud server.

7.3 MDA Coverage Survey

Representative surveys such as MDA coverage surveys will be an important source of data for the estimation of cases of lymphedema and hydrocele. MDA coverage assessments also provide an opportunity to carry out lymphedema and hydrocele assessments. As coverage assessments rely on sampling rather than house to house interviews, the resulting case load would be a representative estimate of the community's burden. However, this can still be a useful exercise to demarcate high burden districts as well as confirm the accuracy of burden assessments carried out during MDA registration.

8 MANAGING MORBIDITY AND PREVENTING DISABILITY: LYMPHEDEMA

ymphedema is a condition in which sections of the lymphatic system malfunction and impair proper drainage of lymph. This in turn results in tissue inflammation and enlargement of the affected limb or area. Severe forms of lymphedema, often known as elephantiasis, include lymphedema affecting a limb so that it becomes swollen, resembling that of an elephant. Elephantiasis is very uncomfortable and disfiguring.

In Ethiopia, there are two major causes of lymphedema, and, while the diseases do have some similarities, there are also significant differences. The most common type due to lymphatic filariasis from the parasitic nematode <u>Wuchereria bancrofti</u> which is transmitted by Anopheles mosquitoes. The second one is podoconiosis, a form of lymphedema arising in barefoot subsistence farmers who are in long term contact with irritant red clay soil of volcanic origins.

8.1 Case Finding

Case finding is one of the important aspects of preparatory work for morbidity management and disability prevention. Lymphedema case findings can occur through active and passive ways (as discussed further in the section 'estimating the number of patients). Active case finding can be done through registration of cases by HEW and HDA through house to house visits. During pre-MDA census case can be further searched and linked with the service providing health facilities. Passive case detection in endemic districts can happen by health workers after providing them training and increasing awareness on the clinical diagnosis of lymphedema.

8.2 Registration

Registration of patients is important for planning, prioritization and monitoring progress. Registration of lymphedema and hydrocele patients can happen during house to house burden assessment and or pre-MDA censuses. Standardized registration books at health post or kebele level is important to register all cases of lymphedema and hydrocele. This registration book should be kept in the health post under the custody of the HEW. However, the number of cases of lymphedema and hydrocele should be reported to the woreda health office.

8.3 Treatment for Lymphedema

Early diagnosis and identification of lymphedema patients and providing early treatment is crucial. Treatment at early stage or acute infection is likely to arrest both the transmission of infection and progression to lymphedema.

8.3.1 Assessment of lymphedema

Understanding the severity of lymphedema is important during the initial assessment and follow-up of patients in addition to the routine assessment of overall health condition of patients (Annex 1). In order to assess the effectiveness of the lymphedema treatment, benchmark information is collected during the first visit. New patients are registered, and the following information is collected and recorded: name, contact address, sex, age, age of onset of condition, clinical stage, presence of moss and presence of wounds/ entry lesions. The entry lesions include inter-digital fungal infection, small wounds, blisters, minor cuts, paronychia, cracks, fissures, eczema, ulcers, scratches on skin folds and others.

8.3.2 Clinical staging of podoconiosis

A system for grading the clinical stages of podoconiosis has been developed and validated[18]. The system has five stages, with the earlier stages defining disease presentation that can easily be reversed with currently implemented treatment packages (Annex 3). The system has been implemented in podoconiosis treatment and control programs in Ethiopia to monitor treatment outcomes.

There are several key words to define and understand before discussing the different stages of podoconiosis. For the sake of staging, these key words are defined as follows:

- Swelling a general increase in the size of the foot or leg.
- Knob/bump a discrete hard lump seen or felt to protrude.
- Moss tiny, rough lesions around the base of the foot that resemble moss.
- Ankle the level of the two ankle bones when standing.
- Knee the level of the top of the knee cap when standing.
- Circumference the greatest below the knee measurement in centimeters.

Staging of podoconiosis was developed from the Dreyer system for staging LF. The Dreyer system[18] of staging did not fit the clinical picture of podoconiosis perfectly, thus five staging system was developed to stage podoconiosis and is used widely in Ethiopia (annex 3).

Each leg is staged independently of the other. First, the clinical stage of the leg is recorded using the above system. Next, presence or absence of moss is documented, using 'M+' if moss is present, or 'M-'if absent. Wounds are checked for, and the observation is recorded as follows: 'W+' if present and 'W-'if not. Finally, a flexible tape measure is used to measure the circumference of the largest point of swelling below the knee. For example a patient with stage 3 podoconiosis, moss, no wound, and a 34cm greatest below the knee circumference would be recorded in the following way: 3, M+, W-, 34.

8.3.3 LF/Podoconiosis essential package

The essential clinical package of lymphedema management includes 5 components (Figure 5) that are the same for LF and podoconiosis patients (one component applicable mostly to podoconiosis patients and one component applicable to LF patients. A psychosocial component of patient counseling is also critical) (Table 1).



Fig. 5. These components are recommended for lymphedema patients at different stages, as outlined in the following table.

Table 1. Components of lymphedema management, by stage

	Mild stage	N	Ioderate stage		Severe stage		With acute attacks
1.	Hygiene	1.	Hygiene	1.	Hygiene	1.	Early detection
2.	Skin care	2.	Skin care	2.	Skin care	2.	Hygiene
3.	Elevation and	3.	Elevation and	3.	Elevation and exercise	3.	Elevation, complete rest
	exercise		exercise	4.	Footwear		to the part and person
4.	Footwear	4.	Footwear	5.	Wound care	4.	Cold application
5.	Wound care (if	5.	Wound care		 Cleaning of entry 	5.	Treating headache, pain
	necessary)		(if necessary)		lesions		and fever
6.	Bandage	6.	Massage		 Applying anti-fungal 	6.	Plenty of fluids
	(optional)	7.	Bandage		or antibiotic creams	7.	Avoid hot application,
7.	Patient		(Optional)	6.	Washing with potassium		exercise, bandaging
	counseling	8.	Patient		permanganate if smelling	8.	Refer if no relief/
			counseling	7.	No scratching/		worsening
			-		puncturing	9.]	Patient counseling
				8.	Patient counseling		

8.3.3.1 Hygiene

Hygiene is a very important aspect of lymphedema management, Thorough and regular washing may reduce the requirement of antibiotics for acute attacks and prevent progression of lymphedema. Good hygiene is important because it reduces the bacterial load, restores the function of the skin, and (especially for podoconiosis patients) removes soil particles from the foot.

Following the basic rules of hygiene as indicated below is advisable:

- Wash both limbs twice daily with clean water at room temperature and ordinary, unperfumed soap. Even if one limb seems to not be affected, it is useful to wash that one as well.
- Wash thoroughly, applying soap from the knee down; take extra care to wash gently in between the toes and folds using a clean cotton cloth or gauze.
- Rinse the limb with clean water.
- Repeat the process of washing with soap and rinsing until the rinse water runs clean to remove all accumulated dirt.
- Gently dry the skin well using a clean towel without rubbing the skin.
- Make sure that the skin between the toes and skin folds are carefully dried.

Some lymphedema sufferers may need help with washing and drying the limb. These cleaning and care techniques also should be used for other parts of the body with lymphedema.

For podoconiosis patients, another step should be added at the beginning. They should soak the feet for 15-20 minutes in a basin with cool, clean water and diluted antiseptic. The type of antiseptic used depends on what is locally available. In some settings, potassium permanganate solution may be available. Careful attention must be given to training patients in accurate dilution of each agent, since any antiseptic may be harmful to the skin if insufficiently diluted. The directions that accompany each antiseptic must be followed when diluting the solution.



Fig. 6:Foot hygiene demonstration

8.3.3.2 Skin care

Caring for the skin helps keep it soft and flexible so that it can act as a barrier to the soil particles that cause podoconiosis and to bacterial and fungal infections. After washing and drying the foot and leg, it is essential to rub the skin with ointment or emollients. Whitfield ointment which is relatively inexpensive and easily attainable from Addis Ababa is used by some partners.

8.3.3.3 Elevation and exercise

The affected limb should be raised at night and when possible during the day and exercised regularly with low-intensity movement of the joints. Elevation is important for patients with lymphedema to prevent the accumulation of fluid in the affected part of the body. Below a very simple measures that can bring considerable relief:

- When sitting, the affected leg should be raised to hip level on a stool or chair, or something similar. The leg should rest in a comfortable manner; if necessary, a pillow should be placed under the knee for support.
- When lying down, the leg should be elevated by placing a support, such as a brick, under the foot of the bed, or a pillow under the mat if the person sleeps on the floor. The entire leg should be raised, not just the foot.
- If the arm, breast or scrotum is affected they can be elevated by placing a pillow or a folded blanket under them at night.

Please note that elevation should not be done if the lymphedema patient is known to have a heart problem.

Immobility significantly worsens the lymphedema condition; patients should be encouraged to keep moving. Frequent exercise of the affected limb will bring relief and can help reduce swelling. The exercises can be done anywhere and at any time, whether sitting, standing or lying down, but should not be done during acute attacks.

The following exercises are recommended and should be repeated 5–15 times each day:

- Standing on both feet and holding onto a wall, tree, chair or person, rise up onto the toes of both feet at the same time and then lower the heels to the ground
- Sitting or lying down, point the toes towards the ground and then flex them upwards, one foot at a time
- Sitting or lying down, move the ankle in a circle, one foot at a time

If these exercises cause pain, the patient should stop doing them.

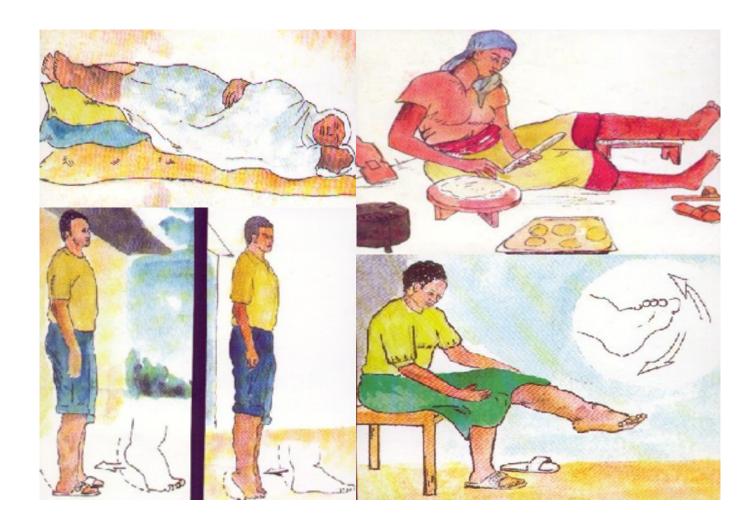


Fig.7. Elevation and movement to improve lymph circulation and reduce swelling

8.3.3.4 Footwear

Socks and shoes are vital for treatment of lymphedema and prevention of podoconiosis. Shoes are the most expensive part of treatment and prevention. As important as shoes are clean socks. Once the socks become dirty it is important to wash them, or they defeat the purpose of keeping irritant soil off the patients' feet. If possible, patients can be supplied with two pairs of socks so that one pair can be washed while the other pair is worn.



Fig. 8. Custom made shoes

The nails and spaces between the toes must be kept clean. Wearing appropriate footwear is important for the following reasons:

- Wearing appropriate footwear will protect the soles of the feet from injury that can lead to an acute attack.
- The footwear should be comfortable, should not be tight, should allow air to circulate around the foot and should have a very low heel.
- Sandals are preferable.
- Lymphedema patients should make sure that the footwear does not cause rubbing or blisters because these can lead to acute attacks. If blisters develop, they should not be punctured and extra care should be taken until they are completely healed.

8.3.3.5 Wound care

An intact skin provides an effective barrier against infection. Lymphedema predisposes to wounds, and wounds occurring in patients are frequently difficult to treat. An excellent and up-to-date World Health Organization guide on Wound and Lymphoedema Management can be found at: http://whqlibdoc.who.int/publications/2010/9789241599139 eng.pdf

Entry lesions

Entry lesions are defined as any break in the skin that enables dirt and germs to enter the body. Small wounds, blisters, minor cuts and scratches are entry lesions. Every time the limb is washed, the skin should be examined for entry lesions that can be very small and hidden in between the toes (or fingers) or folds. In general, patients should avoid scratching the skin. The below advice should be followed:

- Entry lesions should be very carefully washed and dried.
- If an entry lesion is infected, the lymphedema patient should be referred to a Primary Health Care Unit (PHCU) for examination.
- Medicated creams (e.g. antiseptics, antifungal and antibiotic cream) should be used to treat small wounds or abrasions. For patients with elephantiasis, antifungal creams can help prevent fungal infections in deep folds and in the inter-digital spaces.

Other open wounds

There are five basic steps to treating an open wound on a lymphedema patient. It is important to carefully follow each of the steps daily or as often as needed, depending on the severity of the wound.

- 1. Wash hands It is important for the individual treating the wound to thoroughly wash his or her hands. Hand washing is the most important step to prevent spreading infections particularly into the open wound. After washing hands, the individual should dry his/her hands and place on a clean pair of gloves.
- 2. Clean field This is the area to set up the supplies needed for wound care. Place only enough supplies for the one patient. An assistant is very helpful during this step to hand the needed supplies to the person treating the wound. It is important not to touch anything else after touching the wound as this could spread infection.
- 3. Cleanse the wound- It is important to use boiled/sterile water and salt for this step. The water should be boiled for a minimum of five minutes before salt is added to make saline solution and then the wather cooled to room temperature before applying to the wound. The wound should be cleaned using soap and saline solution from the center of the wound outward. It is important to gently remove any yellow or brown tissue from the base of the wound. Be careful not to make the wound bleed by rubbing too hard.
- 4. Assess wound To assess the wound, it is important to measure, smell, and examine/look at the wound.
 - Measure: The wound should be measured vertically, horizontally, and also the depth measured. The measurement should be recorded length x width x depth. A disinfected tape measure should be used for the length and width and a q-tip (cotton bud) for the depth.

- Smell: Smell very close to the wound. A healthy wound should not have any odor, but an infected
 wound may have a bad odor. Occasionally, an infected wound will look green and have a sweet or
 fruity odor.
- Examine/look: Examine the base of the wound. Yellow, brown, or black tissue is dead and should be gently removed for the wound to heal. Conversely, pink tissue is healthy and shows that the wound is healing properly. As it continues to heal, the wound will fill in with red bumpy tissue and eventually new skin.
- 5. Check for infection If present, it is important that the infection is controlled in order to stop it from spreading to the rest of the body. An infection can be controlled by using a number of antiseptics. Zinc oxide is rubbed around the edge of the wound to protect the healthy skin and then Betadine solution or acetic acid solution may be used. If infection is thought to have spread beyond the wound (see red hot leg), then the patient must be referred for systemic antibiotics.

8.3.3.6 Podoconiosis-only extra component: bandaging

Bandaging is highly effective in reducing swelling in most patients with podoconiosis. Each patient must be shown how to bandage or wrap his or her leg, and if unable to do this, someone else in the house or a neighbor must be trained in the proper bandaging technique. The leg should be bandaged from the toes towards the knee, ideally when the leg is elevated. The foot should be wrapped using a "V" shaped design and then bandaging continued in a spiral up the leg to 5cm above the upper limit of swelling, overlapping the previous layer by 50% each full turn around the leg. Podoconiosis project implementing partners are advised to provide patients with two bandages per affected leg so that one may be washed while the other bandage is in use.



Fig.9. Demonstration on how to use bandage for podoconiosis treatment

8.3.3.7 LF-only extra component: anti-filarial treatment

Patients with lymphedema or hydrocele living in LF-endemic areas should be treated during MDA. Otherwise, all people with filariasis who are positive by antigen test or have microfilaremiacan receive individual anti-filarial drug treatment to eliminate microfilariae. They can be treated with a single dose of a combination of Albendazole (400 mg) with Ivermectin (150–200 μ g/kg).

8.3.3.8 Treatment for acute attacks

There are certain measures that can be taken to prevent and reduce the severity of acute attacks (Annex 4). These measures consist of educating lymphedema patients and their families and friends in how to care for the limbs (or other parts of the body) during acute attacks.

Pain relief

- Pain relief is obtained by cooling the affected limb or other part of the body either by applying a clean cloth soaked in cold water and changing it as soon as it becomes warm, or by soaking the affected part in a bucket of clean cold water. The cooling process should continue until the pain subsides
- Medicine can be given to bring down the fever, for example, Paracetamol.

Hydration

• The lymphedema patient should drink plenty of water

Rest

• The patient should rest, elevating the affected part of the body as comfortably as possible

Antibiotics

• Antibiotics -usually penicillin-should be used as a method of treatment if pain and fever do not subside after 24hrs or shivering and confusion arises.

Do Not do the following:

- Exercise
- Putting anything that is warm or hot on the skin
- Open or cut a blister, or cut the skin for any reason
- Bandage the leg
- Rub herbs, ashes, or anything else on the skin that has not been advised by a doctor or nurse.
- Scarification should never be used

8.3.3.9 Referrals for acute attacks

Indications for referral for acute attacks include the following:

- High grade fever
- Confusion
- Vomiting
- Pregnancy
- Unresponsive after 48hrs of treatment
- Abnormal heart rate
- Abnormal breathing rate
- Abnormal blood pressure

8.3.3.10 Patient counseling

The psychological effects of lymphatic filariasis and podoconiosis have not been well recognized[19-21]. Psychological support and socioeconomic rehabilitation are necessary to complement the medical and surgical care of these patients so that they can achieve full integration into their community by overcoming the psychological consequences of stigma and discrimination. As the impairments and disability associated with lymphedema and hydrocele often lead to reduced capability, these patients need assistance in finding suitable jobs.

The support provided depends on the needs of the patient in relation to her/his community. It may include the following:

- a) Individual patient counseling
- b) Patient support groups where individuals may exchange their experiences or offer advice to one another. Therefore, program staff need to:

- Link the patients to micro and small enterprise development offices so as to ensure that they get vocational training and access to micro-finance services. This would enable them to start small businesses like shoemaking, hairdressing, carpenter and other viable income generating activities;
- Organize social mobilization to address the potential psychological impact of the chronic complications of lymphatic filariasis or podoconiosis;
- Organize training for health care workers and community health workers (HEWs and HDA) on psychological support techniques;
- Refer patients for advanced psychological therapy where necessary.

8.3.3.11 Follow-up / monitoring

Patients should report to the clinic or be visited by a health worker in their home once a month for the first three months in order to obtain more treatment supplies and to monitor progress. During follow-up visits at the clinic or at patients' homes, health workers should be keen to detect entry lesions, remind patients and their families of the basic management techniques, and emphasize prevention and early care.

Progress is recorded in the register adjacent to the previous month's scoring so that the two can be compared. During follow-up, patients have conversations among themselves about what they have done and observed in their own communities over the past month. This exchange of ideas is vital among patients and patient associations.

After three months, patients should be followed up every 12 months to address any issues and ensure compliance with the basic self-care routine. This follow up can be done by having patients come to the health center or by visiting the patients in their homes.



Fig. 10. Health worker while collecting benchmark information

8.3.3.12 Referrals for lymphedema patients

Health centers can refer patients for a variety of reasons, including:

- Patients with complicated lymphedema
- Patients needing minor surgery, especially with Podo patients to remove nodules
- Patients with deep fungal infection, manifested as additional lumps which do not respond to regular treatment. The patient should be referred to a surgeon for a biopsy, anti-fungal treatment or amputation.
- Patients with psychological problems, including depression
- To micro and small enterprise development office

The following chart shows how referrals should be done.

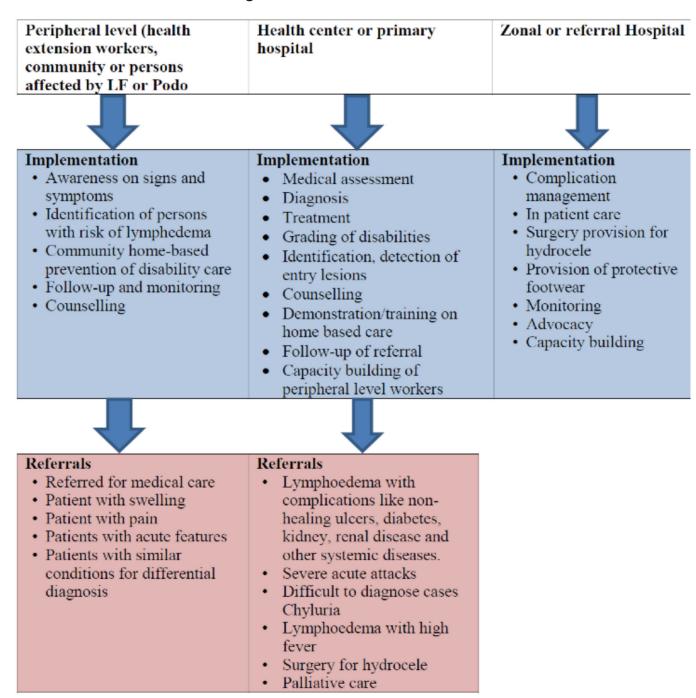


Fig 11. Referral pathways for lymphedema management

8.3.3.13 Service delivery approaches

Two types of delivery strategies can be used to manage lymphedema: primary health center based care or home/community based care. The choice of these approaches depends on the number and geographic distribution of patients and the capacity of the health system. Primary health-based care: In this approach, patients come to health centers or primary hospitals to seek training, care, and monitoring of their condition. The patients are also treated for acute attacks or any complications at the health center or primary hospital. Staff at the health facilities should monitor the patients at every month for three months after initial training

and then at 12 months.

- Home/community-based care: Family home-based care involves a family member in the training, follow-up and monitoring of the lymphedema patient. The patient is also part of the training and takes part in taking care for him/herself through basic hygiene and skin care. Care of an affected part needs to be taken throughout life, often assisted by the patient's family and community. Inspection of the affected part needs to be done daily and intensely to detect the points/sites of the entry lesions, especially the inter-digital spaces and the skin folds. If complications or acute attacks occur, these patients should visit the nearest health center to seek further care.
- Patient support groups: Dedicated patient associations will allow the care, treatment and prevention of lymphedema patients to scale-up quickly by involving communities and reaching a larger geographic coverage whilst ensuring sustainability. These associations create solidarity amongst the patients and give them the power to fight the stigma and discrimination they are facing due to the disease. In addition, practical experiences have shown that patient associations are important for the follow-up of patients and ensure adherence to self-treatment, empower the patients economically and shorten the treatment period significantly. In endemic districts, patient associations are formed at kebele-level and they come together under the umbrella of the woreda-level patient associations, which coordinates the activities of the kebele-level patient associations. The associations are involved in prioritizing individual patients for MMDP based on the severity of their condition, follow up self-care and also, trace dropout cases. In addition, patient associations educate the community about the disease to reduce stigma and discrimination.

In all approaches, the responsibilities of the health centers include:

- Involvement in confirming suspected cases identified by HEWs or self-referred cases.
- Assessment and management of acute lymphangitis
- Training of the peripheral health staff/patients/family members for early management and referral.
 - o Education and building the skill of the patient or other family member through demonstration of the actual practice by performing the above management packages.
- Supervision of HEWs and HDA in providing health education messages and identifying suspected patients
- Supervision of patients and families in managing the lymphedema

The responsibilities of HEWs and HDA include:

- Identification and referral of cases;
- Identifying the barriers and act on ignorance, stereotypes and discrimination that exist at various levels;
- Encourage the family members of cases and their communities for early identification, treatment adherence and disability care;
- Sensitizing the community on lymphatic filariasis and podoconiosis prevention, control &treatment;
- Counseling patients on MDA and disability care;
- Provide feedback on quality of services;
- Act as positive speakers or 'change agents' to dispel negative attitudes, beliefs and practices amongst service providers and in the community;
- Sensitize the persons affected by LF and podoconiosis about collectivism and encourage them to be part of/enroll in self-support groups/networks.

9 MORBIDITY MANAGEMENT AND DISABILITY PREVENTION: HYDROCELE

hydrocele of the scrotum in filariasis (also known as filaricele) presents as an accumulation of fluid in the membrane sac (tunica vaginalis membranes) that surrounds each testicle, the tunica vaginalis. It may be either unilateral or bilateral; or associated with elephantiasis of the scrotum (where the scrotal skin is affected). The initial presenting sign is swelling that can be temporary at first, but becomes permanent within a relatively short time. A positive transillumination test is useful, but a negative reading does not necessarily rule out a diagnosis of an LF hydrocele. An LF hydrocele can cause considerable pain and limitations to the physical activity of those affected and, if untreated, may give rise to complications such as pyocele, chylocele, haematocele, and calcification of the sac.

9.1 Case Finding

Case finding is among the important aspects of preparatory work for morbidity management and disability prevention. The case findings of hydrocele can occur through active and passive case finding. Active case findings can be done through registration of cases by HEWs and the HDA through house-to-house visits. In addition, during pre-MDA censuses cases can be searched and linked with the service-providing facilities. Passive case detection can occur through training of health providers in endemic districts on the clinical diagnosis of hydrocele. The diagnosis of hydrocele should be integrated with routine outpatient check-ups and specialized services such as sexually transmitted infections clinics.

9.2 Registration

Registration of patients is important for planning, prioritization and monitoring of progress. Registration of lymphedema and hydrocele cases can happen during house-to-house burden assessments and or pre-MDA censuses. Standardized registration books at kebele-level are important to register all cases of lymphedema and hydrocele. This registration book should be kept in the health post under the custody of health extension workers. Whilst the number of cases of lymphedema and hydrocele is reported to the woreda health office.

9.3 HydroceleTreatment

The critical management of hydrocele is surgery. The vast majority of cases of hydrocele in lymphatic filariasis endemic regions can be managed surgically by primary hospital surgical facilities; however, there are certain cases that are considered to be 'complicated cases'. These complicated cases are more difficult to treat medically and surgically, they are relatively rare, and need to be referred to the General Hospital level to be operated on by a surgeon specialized in urogenital conditions (Annex 5).

9.4 Algorithm for hydrocele treatment

The initial step for providing service in relation to hydrocele is the identification of patients. An accurate diagnosis of hydrocele can usually be made solely on the basis of physical findings. The examination of the scrotum consists of direct observation, clinical examination and palpation; aids such as transillumination, and ultrasound can be useful when available, but are highly examiner-dependent and not universally reliable.

9.5 Follow-up

After the wound heals and the patient is deemed well following the immediate post—operative follow-up at Day 14, monthly follow-up is recommended for two months, with further follow-up at six months and one year.

Nonetheless, the surgical outcome of these patients' should be followed up by the National NTD Programme as part of their regular M&E exercises.

9.6 Referrals

The referral path for hydrocele will follow the service delivery pathway indicated below. Health centers will identify cases and refer these cases to the primary hospital. The primary hospital will conduct hydrocele surgery and refer any complicated cases to the general hospital.

9.7 Service Delivery

Different levels of the health system play important roles in management of hydrocele:

Health Center Level (Level 1)

Level I facilities, which are a complex of health posts and a health center, are responsible for the following activities (usually carried out by HEW, HDA or Health Officers):

- Detection of suspected cases record all patients with scrotal swelling(s) following active and/or passive surveillance, and refer them (often via the Health Officer in some cases for those identified by HEW and HDA) to the Primary Hospital (Level 2) for confirmation of a probable diagnosis of LF-Hydrocele by a Medical Officer.
- Provide key messages to patients regarding the options of care and the basic procedures and actions that may take place in administering their care, such as:
 - o Further care for scrotal swellings is available at a Primary Hospital.
 - o That surgery is an outpatient procedure with patients being discharged after 1-2 hours.
 - o That there will be follow-up examinations: Firstly, at 48 hours at the Primary Hospital, and thus may need the patient staying near at the Primary Hospital for two days. At 7 days, the patient needs to be again examined and the sutures removed, either at the Primary Hospital site or at the Health Center.
 - o Provide advocacy and medical follow-up support for patients after surgery (HEW, HDA and appropriately trained Nurses from Primary Care Hospitals can all be involved in this activity).

Primary Hospital (Level II, and Hydrocele Camps where they are used)

Level II facilities, which are usually Primary Hospitals or perhaps surgical camps, are sites staffed by Medical Officers, Health Officers, Nurses and others associated personnel. These are sites capable of carrying out the needed surgery on the non-complicated LF-hydrocele cases. The general requirements at this location are as follows:

• Have a room in which minor surgical procedures are conducted under local anesthesia (in this case

routine hydrocelectomies)

- Facilities for post-operative observation of patients for 48 hours
- The capability of performing basic laboratory tests to aid in detecting anemia and diabetes (Hb, dipstick urinalysis).
- To have essential resuscitation equipment and drugs available
- Ability to autoclave instruments, or in the absence of this, a supply of pre-sterilized surgical instrument packs
- Additional surgical equipment, such as diathermy, suction apparatus, is encouraged.

In addition to providing surgical services for uncomplicated hydrocele cases level II facilities are responsible for the following activities:

- Leading the mapping and identification of cases at community levels
- Training activities to build the capacity of health extension workers in mapping and identification of cases
- Provide information on the importance of surgery and supervise/carry out patient follow-up
- Collaborate with general hospitals for referral of complicated cases and program review

General hospital (Level III)

These institutions are equivalent to the zonal or referral hospitals, where patients with more serious problems, such as a complicated hydrocele, can be operated on and other associated complications addressed. In addition to providing surgical services for complicated hydrocele cases, level III facilities are responsible for the following activities:

- Building capacity of health workers at level II in mapping and identification of cases and in providing surgical services for uncomplicated cases
- Supervisors should be those involved in the training.
 - o Zonal level NTD focal points should be involved.
- Provide information on importance of surgery and case follow up

10 ROLES AND RESPONSIBILITIES OF STAKEHOLDERS AND PARTNERS

10.1 Federal Ministry of Health

- a) Chair the National LF/Podoconiosis Technical Working Group (TWG);
- b) Design a national LF and podoconiosis control/elimination program, that includes MMDP;
- c) Mainstream the MMDP services within the existing health system (PHCU, Health Extension Program, HDA);
- d) Institute and ensure quality assurance mechanisms for MMDP services;
- e) Engage relevant government agencies for the achievement of the national MMDP goals and objectives;
- f) Create an enabling environment for public-private partnerships for scaling-up LF and podoconiosis MMDP interventions;
- g) Standardize training materials and tools;
- h) Ensure continuous availability of essential medical equipment, medical supplies and drugs in health facilities within the endemic districts;
- i) Mobilize resources from within and outside the country for the implementation of MMDP interventions;
- j) Provide support in the importation and custom clearance of MMDP pharmaceutical logistics;
- k) Coordinate the implementation and regular review of LF and podoconiosis MMDP interventions.

10.2 Micro and Small Scale Enterprise Offices at Regional, Zone and Woreda levels

- a) Provide vocational and micro-business management training to LF and podoconiosis patients and/or affected families;
- b) Provide LF and podoconiosis patients and/or affected families with advisory services on micro and small-scale enterprises;
- c) Undertake value-chain market assessments and advise patients accordingly;
- d) Facilitate access to micro-financial services to rehabilitated LF and podoconiosis patients and/or affected families;
- e) Facilitate market linkage with government, private and other relevant development partners;
- f) Provide and facilitate access to relevant technologiesforLF and podoconiosis patients and/or affected families.

10.3 Non-government Development Partners (NGDOs)

- a) Provide support for improving MMDP service quality and coverage for persons affected by LF and podoconiosis;
- b) Integrate MMDP in to their health and development interventions;
- Support for innovative and cost-effective strategies to increaseaccess to, and utilization of MMDP services;

- d) Enhance meaningful participation of individuals, families and communities affected by LF/podoconiosis in MMDP services;
- e) Strengthen referral and linkage mechanisms so as to ensure individuals affected by LF/podoconiosis have access to medical, socioeconomic and psychological services;
- f) Mobilize resources for scaling up MMDP interventions and virtuous practices;
- g) Provide support to develop the MMDP capabilities of program managers, medical and health workers.

10.4 Academic and Research Institutes

- a) Conduct research on the impact and outcomes of services, alternative treatments, and prevention mechanisms;
- b) Provide scientifically sound evidence and facts for informing policy and national strategy formulation;
- c) Include MMDP within the pre-service health and medical training curriculum.

11 MONITORING AND EVALUATION FOR LF AND PODOCONIOSIS MMDP ACTIVITIES

rogram managers of institutions that undertake lymphatic filariasis and podoconiosis morbidity management and disability prevention shouldmonitor the interventions so as to ensure that progress is in the right direction for achieving the objectives of the program and that the best outcome for patients is achieved.

Proper supervision of each activity and close monitoring and evaluation needs to be in place during the planning and implementation of the program. This includes assessing the results of mapping, reported cases and actual coverage, as well as impact assessments.

11.1 Performance Indicators

11.1.1 Indicators for hydrocele surgery

#	Performance indicator	Data Source	Indicator Definition	Reporting Frequency	Site for Reporting	Data Collection Method	Responsible	Remarks
	Number of health care professional trained for hydrocele surgery	RHB HRH records	Disaggregated by: 1) # of surgeons trained 2) # of general medical practitioner and health officers trained 3) # of nurses/surgical assistants trained	Quarterly	RHB	Reviewing hospital records; Supervision visit reports	LF/NTD Focal Person	Process/ Surgery quality indicator
7	Percentage of people under- gone hydrocele surgeries ofthose LF affected and needing surgery	HMIS; Project implementing partner reports	Numerator: Total number of hydrocelectomies Denominator: Total number of patients with hydroceleand with indication for surgery [hydrocele backlog for surgery]	Quarterly	RHB	Reviewing health facility/ Woreda Health Office reports (combine surgical intervention at camps with that of the health facility level)	LF/NTD Focal Person	Outcome
3	Number of hydrocele patients with complications within 7 days of surgery	Hospital records	Total number of patients who developed infection/hematoma/ other complications within the first 7days of hydrocelectomy	Quarterly	Hospital	Reviewing hospital records; Supervision visit reports	LF/NTD Focal Person	Surgery quality indicator
4	Number of designated health facilities for provision of hydrocele surgery by woreda	HMIS; Project implementing partner reports	Actual number of health facilities capable of providing care for hydrocele patients per woreda	Quarterly	RHB	Hospital and health centers records; Supervision visit reports	LF/NTD Focal Person	Process/ Service quality indicator

11.1.2 Indicators for lymphedema management

Remarks	Process/ Service quality indicator	Process/ Service quality indicator	Outcome/ Quality indicator	Outcome/ Quality indicator	Process/ Service quality indicator
Responsible	LF/Podo Focal Person	LF/Podo Focal Person	LF/Podo Focal Person	LF/Podo Focal Person	LF/NTD Focal Person
Data Collection Method	Reviewing hospital and health center records; Supervision visit reports	Reviewing health facility records	Reviewing health facility records	Reviewing health facility/ Woreda Health Office reports	Hospital and health centers records; Supervision visit reports
Site for Reporting	RHB	Health facility	Health facility	RHB	RHB
Reporting Frequency	Quarterly	Quarterly	Quarterly	Quarterly	Quarterly
Indicator Definition	Disaggregated by: 1) # of health care providers category/profession 2) # of nurses/surgical assistants trained	Number of patients with any stage of lymphedema in a woreda	Numerator: Number of patients who are trained on self-morbidity management and returned for 3-month follow-up Denominator: Total number of patients who are trained on self-morbidity management	Numerator: Number of lymphedema patients that were treated for an acute attack at health facility (implementation unit) Denominator: Total number of lymphedema patients registered at health facility (implementation unit)	Actual number of health facilities capable of providing care for lymphedema patients per woreda
Data Source	RHB HR records	Health facility report; Implementing partners project report	Health facility report; Implementing partners project report	HMIS	HMIS; Project implementing partner reports
Performance Indicator	Number of health care professionals trained for lymphedema management in an implementation unit/ health facility	Number of patients with lymphedema identified in an implementation unit (health facility)	Percentage of lymphedema patients under care and trained on morbidity management who returned for the 3rd month of followup at a health facility (implementation unit)	Percentage of lymphedema patients treated for acute attacks at a health facility (implementation unit)	Number of designated health facilities for provision of lymphedema management by woreda
#		7	8	4	v

11.1.3 Registers and Reporting FormatsFollowing table illustrates the main registers and reporting formats that need to be implemented at district and health facility level:

Document	Name of the	Level	Purpose	How it will be used
#	Document		4	
1	Patient card	PHCU	A patient card will be provided to the health workers to make a record of persons having manifestations of filariasis such as lymphoedema, hydrocele, etc.	To identify the activities/ services required and to plan follow-up visits
2	Line listing of pa- tients	PHCU	To record and line list the new cases in the community/district	Incidence and prevalence of LF cases
3	Referral register and format	PHCU / Hospital	To refer LF patients to access services and care For early identification and treatment	For early identification and treatment
4	Follow-up Register	PHCU	To track the patient information, treatment adherence, self-care, treatment outcome	To know the progress and improvements
5	Reporting format for lymphoedema morbidity management and hydrocele cases	District/ Region	Summary of the cases identified during the quarter and details of morbidity management	To know the magnitude of the problem, decision-making, plan and implementation of activities
9	Training register	District	Information about medical and paramedical trained on LF, morbidity management	To enhance the skills of the health staff, medical and paramedical staff, and community/family members to deliver services to the patients

11.1.4 Measuring Tool for LF-related Disabilities

Disability measurement tools, presently applied in LF are more generic and include International classification of functioning disability and health (ICF), World Health Organization Disability Assessment Schedule (WHODAS), World Health Organization Quality of Life (WHOQOL)[22]. LF affects the social life of the individual, hence 'social participation' as an additional domain was incorporated in an already existing tool 6D5L[23]to evolve the latest 7D5L version[24]. This instrument comprises seven health domains (mobility, self-care, usual activities, pain anxiety/depression, cognitive function and social participation) that encompass physical, mental and social aspects. The severity of each domain is scored assigning '0, 1, 2, 3 and 4' for 'no, hardly, somewhat, quiet and extreme bothering', respectively. The total score for the seven domains ranges from 0 to 28 representing either no problem or a severe problem, respectively. The following format can be used for recording the findings:

7D5L for L4 (for example)							
Extent of	Domains						
Bothering	Mobility	Self-care	Normal activity	Pain	Anxiety	Social participation	
Extreme							
Quite							
Somewhat							
Hardly							
No							

An affected man may be suffering from either lymphoedema or hydrocele or both. If female, she may suffer from either lymphoedema of the limbs, breast or genitals, or all. Some may have ADLA with single or multiple attacks. Through an appropriate questionnaire, the information in each of the seven domains, from any of the six grades of lymphoedema and hydrocele can be captured. The disability weight of a person can be captured in a table (shown above) through a visual analogue scale and averaged as detailed in the article. For applying this new tool, disability was graded in ascending order as L1, L2, H1, L3, H2, L4 and ADLA (H for hydrocele and L for lymphoedema).

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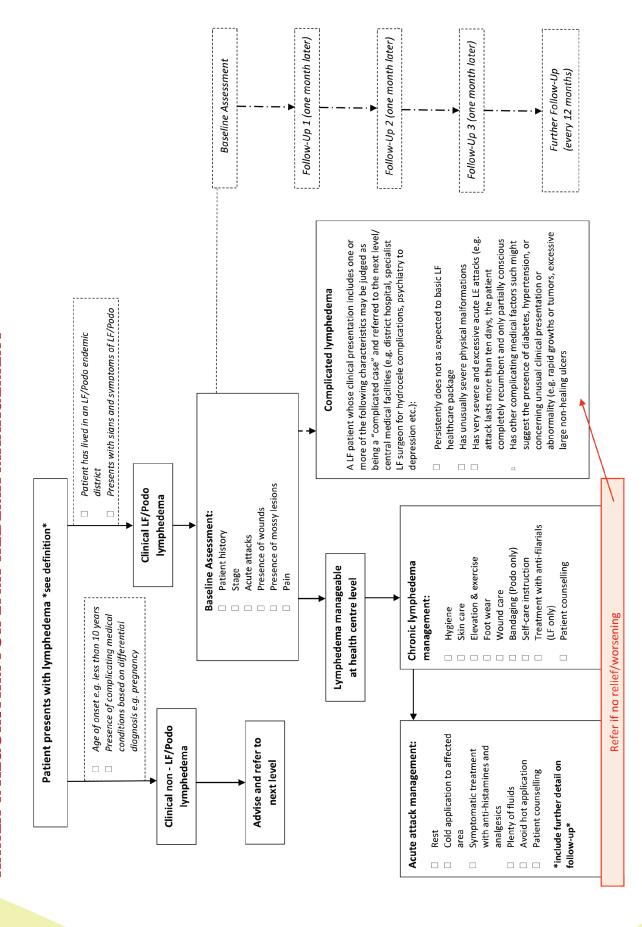
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Annexes

- Annex 1: Algorithm for lymphedema management
- Annex 2: Clinical staging of LF lymphedema
- Annex 3: Clinical staging of podoconiosis lymphedema
- Annex 4: Algorithm for acute dermatolymphangioadenitis (ADLA) management
- Annex 5: Algorithm for hydrocele management
- Annex 6: Equipment and Supplies for Lymphedema Management & Hydrocele Surgery
- Annex 7. A) Mossy foot B) Podoconiosis patients with nodule C) Water bag type swelling
- Annex 8: Endemicity map of Lymphatic filariasis in Ethiopia
- Annex 9: Endemicity map of Podoconiosis in Ethiopia

ANNEX 1: ALGORITHM FOR LYMPHEDEMA MANAGEMENT



ANNEX 2: CLINICAL STAGING OF LF LYMPHEDEMA

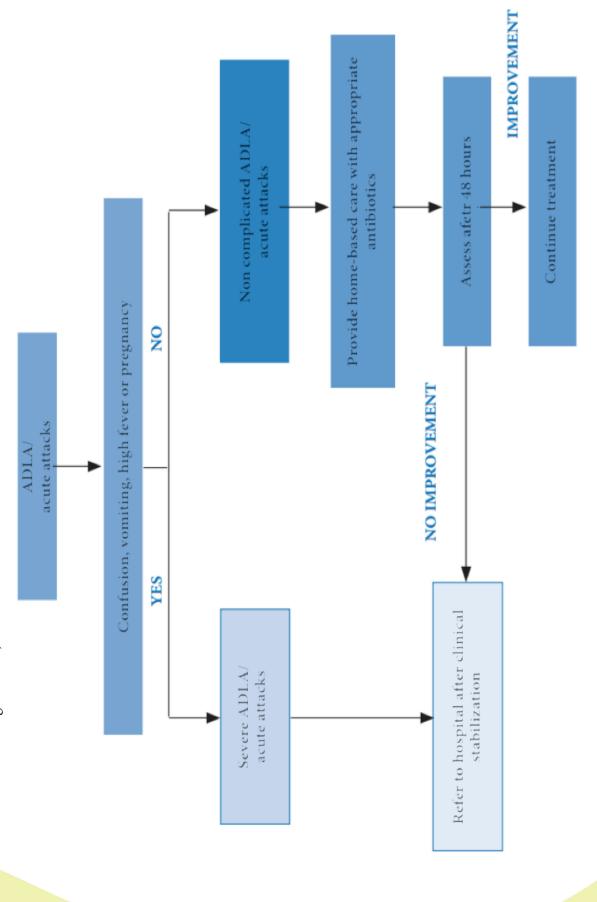
STAGE	CHARACTERISTIC CLINICAL FEATURES	IMAGE
1	Swelling is reversible (goes away) overnight	
2	Swelling is not reversible (does not go away) overnight	
3	Presence of shallow skin folds (base of fold can be seen with leg movement)	
4	Presence of skin knobs	
5	Presence of deep skin folds (base of fold can only be seen if opened up)	
6	Presence of "mossy lesions". Warty looking epidermal skin lesions	
7	Unable to care for self or perform daily activities (social disability)	(2)

ANNEX 3: CLINICAL STAGING OF PODOCONIOSIS LYMPHEDEMA

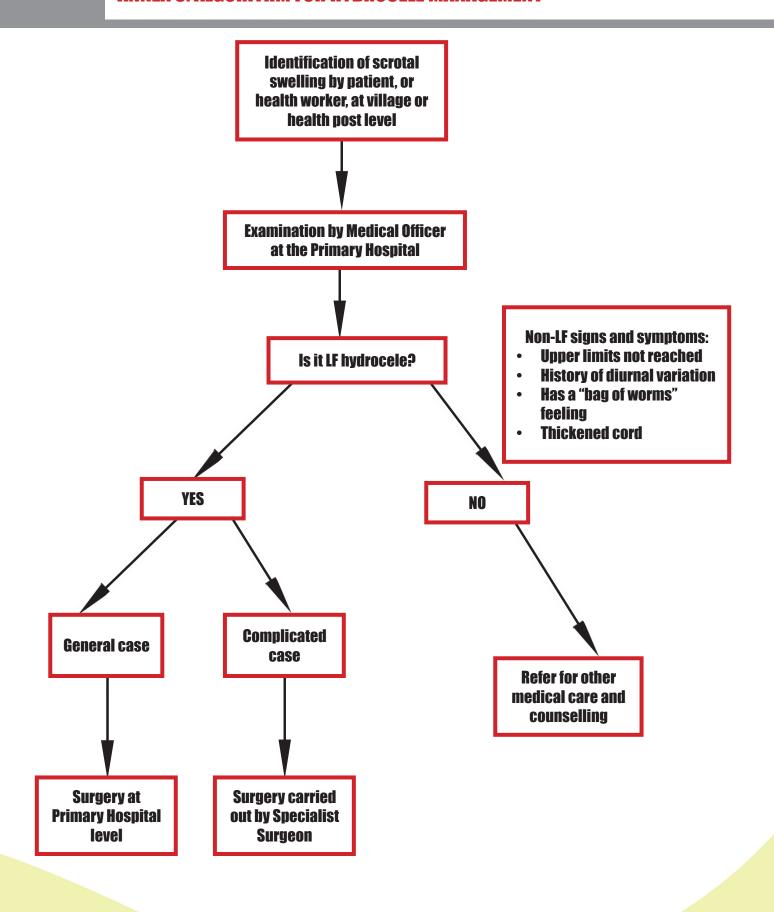
STAGE	CHARACTERISTIC CLINICAL FEATURES	IMAGE
1	Swelling reversible overnight. The swelling is not present when the patient first gets up in the morning	
2	Below-knee swelling that is not completely reversible overnight; if present, knobs/bumps are below the ankle only	
3	Below-knee swelling that is not completely reversible overnight; knobs/bumps present above the ankle	
4	Above-knee swelling that is not completely reversible overnight; knobs/bumps present at any location	
5	Joint fixation; swelling at any place in the foot or leg. The ankle or toe joints become fixed and difficult to flex or dorsiflex. This may be accompanied by apparent shortening of the toes	

ANNEX 4: ALGORITHM FOR ACUTE DERMATOLYMPHANGIOADENITIS (ADLA) MANAGEMENT

(Taken from Lymphatic filariasis: managing morbidity and preventing disability. An aide-mémoire for national programme managers. World Health Organisation)



ANNEX 5: ALGORITHM FOR HYDROCELE MANAGEMENT



ANNEX 6: EQUIPMENT AND SUPPLIES FOR LYMPHEDEMA MANAGEMENT & HYDROCELE SURGERY

Washing kit for lymphedema management should consist at least the following:

- Basin
- Soap and
- Clean cotton cloth or gauze
- Bandages

Equipment and Supplies required for hydrocele surgery

Kits for hydrocelectomy	
Disposable and drugs	Instruments
1) Syringe (10ml) 2pc 2) Syringe (50ml) 2pc 3) Needles, 20G 2pc 4) Needles, 24G short 2pc 5) Needles, 24G long 2pc 6) Disposable drapes, small 2pc 7) Disposable drapes, large 2pc 8) Sterile gowns 2pc 9) Surgeon's cap 2pc 10) Surgeon's mask 2pc 11) Non-permeable apron 2pc 12) Trolley towel 2pc 13) Surgeon's gloves 4 pairs 14) Dressing materials 15) Gauze pieces 16) Surgical sutures 00 chr. catgut 17) Surgical impregnated hand wash brushes 2pc 18) 2% Lidocaine with adrenaline	1) Sponge-holding forceps 2pc 2) BP handle with blade 2pc 3) Dissecting forceps, toothed 1pc 4) Dissecting forceps, non-toothed 1pc 5) Towel clips 4pc 6) Metzenbaum scissors 1pair 7) Mayo's scissors 2pair 8) Trocar and cannula 1pc 9) Curved artery forceps 8pc 10) Straight artery forceps 2pc 11) Allis forceps 2pc 12) Needle holder 1pc 13) Steel kidney tray 1pc
19) Povidone iodine solution for topical preparation20) Tetanus toxoid 1 ampoule21) Antibiotics for 5 days	
22) Analgesics for 2 days	

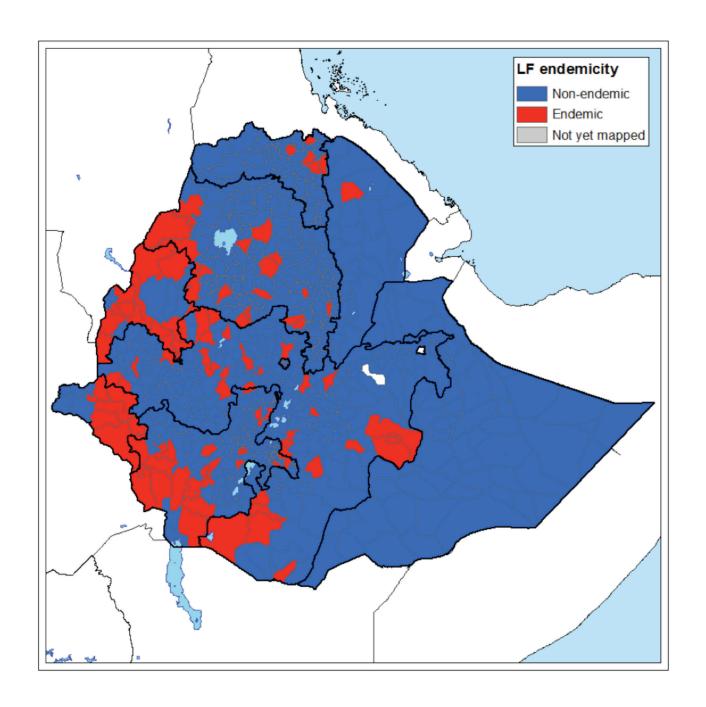
ANNEX 7: A) MOSSY FOOT B) PODOCONIOSIS PATIENTS WITH NODULE C) WATER BAG TYPE SWELLING







ANNEX 8. ENDEMICITY MAP OF LYMPHATIC FILARIASIS IN ETHIOPIA



ANNEX 9. ENDEMICITY MAP OF PODOCONIOSIS IN ETHIOPIA

