District NTD Training module

Learner’s Guide

Module 6: Morbidity Management and Disability Prevention (MMDP)

Session 2: Lymphoedema Management

Part I: Introduction

Session Purpose:

This session is designed to give an overview of lymphoedema diagnosis and management for district-level health and public health staff. The focus is on case finding and clinical care.

Prerequisite modules/sessions:

Module 1, Session on Lymphatic Filariasis
Module 6, Session 1: Planning MMDP Activities at District Level

Learning Objectives:

By the end of this session, participants will understand:

- How to diagnose and treat lymphoedema and acute attacks
- How to assess burden and find cases of lymphoedema
- How to monitor and evaluate lymphoedema management activities

Abbreviations and acronyms:

- ADL: adenolymphangitis, including acute dermatolymphangioadenitis (ADLA) and acute filarial lymphangitis (AFL)
- GPELF: Global Programme to Eliminate Lymphatic Filariasis
- LF: lymphatic filariasis
- M&E: monitoring and evaluation
- MDA: mass drug administration
- MMDP: morbidity management and disability prevention

Definitions:

- *Adenolymphangitis*: acute forms of lymphatic filariasis, including acute dermatolymphangioadenitis (ADLA) and acute filarial lymphangitis (AFL)
- *Lymphoedema*: swelling caused by the collection of fluid in tissue, most often in the legs or arms
Part 2: Key Concepts

Lymphoedema

What is lymphoedema?

- Lymphoedema is swelling caused by the collection of fluid in tissue. In LF, the parasitic worms damage the lymph system and predispose the limbs to recurrent bacterial infections, which can cause a build up of fluid in the limbs (legs, arms). This happens more commonly in women than in men.
- Severe lymphoedema is called elephantiasis.
- Lymphoedema of the genital organs is less common and requires more specialized care. It will not be covered in this module.
- There is no diagnostic test to confirm if lymphoedema is caused by LF, but care for the lymphoedema is the same regardless of the cause.

What are the consequences of lymphoedema?

- People with lymphoedema are often unable to complete basic daily activities.
  - They can be unable to move.
  - They can have smelly limbs.
  - They sometimes cannot work.
- This contributes to reduced productivity in the community, but can be improved by appropriate care of patients.
- People with chronic manifestations often feel stigmatized and therefore hide their condition.
  - They can be depressed.
  - They can be isolated in their houses.
They can have trouble finding marriage prospects.

- While annual mass drug administration (MDA) is used to interrupt transmission of LF, patients with lymphoedema need more continual care through the health system.
  - MDA is usually implemented by the public health disease control district staff, but it is usually nurses and doctors – or trained family members- who care for patients with lymphoedema.

**Lymphoedema Activities**

- Find suspected cases
- Diagnose cases
- Manage lymphedema
- Monitor and report
- Evaluate

*See Powerpoint slide for more information.*

**Diagnosis**

**LF’s effect on lymphatic system**

- The lymphatic system has 2 functions: 1. transport waste and excess fluid produced in the body, and 2. fight infections as part of the body’s defense system

- Worms cause dilation of lymph vessels, which causes stasis of lymph liquid and an accumulation of liquid around the tissues.

- Body’s defense system does not function effectively and can’t fight bacteria that enter through lesions and wounds. This leads to inflammation of the skin, which is worsened by the damaged lymphatic system

**Diagnosis of lymphoedema**

- Not linked with presence of parasite
  - Patients might not have microfilaraemia, antigen or antibodies to LF
  - Usually appears 5-10 years after infection

- A swelling of limb or other affected body part, which can be accompanied by any of the following:
  - Tension of the skin
  - Deep skin folds
  - Skin lesions (cuts, wounds, nodules, roughness)
  - Secondary infections of wounds, sometimes with bad odor
  - Inability to use the limb

- Depending on severity, may or may not be reversible
## Stages of Lymphoedema

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
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<tbody>
<tr>
<td>1</td>
<td>Swelling disappears overnight without treatment. No visible entry lesions, acute attacks or bad odors</td>
</tr>
<tr>
<td>2</td>
<td>Swelling is irreversible</td>
</tr>
<tr>
<td>3</td>
<td>Swelling is permanent with shallow skin folds</td>
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<tr>
<td>4</td>
<td>Swelling is permanent with nodules on the skin</td>
</tr>
<tr>
<td>5</td>
<td>Swelling is permanent with deep skin folds</td>
</tr>
<tr>
<td>6</td>
<td>Swelling is permanent with mossy lesions on the skin</td>
</tr>
<tr>
<td>7</td>
<td>Patient is unable to perform daily activities</td>
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</table>

## Burden Assessment
The following table shows the positives and negatives of different methods to assess the number of cases of lymphedema that exist in a district. These methods can be used if the information already known in the district is not enough to make decisions about platforms of care to use or supplies needed.

**Physical examination** is the best way to determine if someone has lymphedema in previously or currently LF endemic areas. Survey questionnaires, with photos, can also be used, but often underestimate the number of patients.

<table>
<thead>
<tr>
<th>Method</th>
<th>Pros</th>
<th>Cons</th>
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| Census by community health workers/pre-MDA registration | - Most comprehensive method if done well, can get line listing of cases | - Patients need to be followed up by trained nurses or doctors to confirm diagnosis  
  - Data often do not make it past the health center level to higher levels |
| Post-MDA coverage survey or TAS             | - Provides prevalence estimate                                          | - Self-reported patients need to be followed up by health staff to confirm  
  - Easier to include in community-based TAS than school-based TAS |
| Population-based national surveys           | - Provides prevalence estimate                                          | - Still need to find all the cases  
  - Can add a few questions about LF morbidity to another survey, such as the WHO disability model survey  
  - Has to be coordinated at a national level  
  - Timing depends on health programme implementing the survey |
| Key informant interviews                    | - Flexible, low cost                                                   | - Large variations in accuracy  
  - Possibility of underreporting of cases |
| Chart review at district health facilities  | - Can collect other information on cases such as age, gender, stage  
  - Low cost                                                           | - Will likely be underestimate as patients may not have come to health centers for treatment  
  - Can be time-intensive, depending on chart system  
  - Can be incomplete based on availability of data |
Active case finding

- Districts might need to use active methods to find all lymphedema cases, such as purposively targeting hard to reach areas or conducting door-to-door screening. The district should use the local terms for lymphoedema or elephantiasis.

- What is the main message during active case finding?
  - Individuals with swollen limbs or big foot to report to nearest health center

- How is this message disseminated?
  - Village chiefs
  - Town criers
  - Radio broadcasts
  - Trained community health workers/volunteers going door-to-door
  - Posters at health centers, posts and dispensaries

- How are patients registered?
  - Suspected patients confirmed by trained nurse
  - Recorded in LF consultation register
  - Can be given individual patient booklets

Lymphoedema Management

What can be done for a LF patient with a chronic swollen limb?

- The lymphatic system drains excess water from extremities (arms, legs) back to the heart. It also defends against infections caused by bacteria. When it is damaged by LF infection, fluid can build up in legs and arms, leading to swollen legs or arms with cracked skin.
• Cleaning and caring for skin is necessary to decrease the possibility of developing secondary infections. Secondary infections happen because lymphoedema patients can easily develop wounds and their immune defense systems do not function properly.

• Patients must manage lymphoedema throughout their lives, so they must learn how to care for themselves.

• These are the top five most important activities for lymphoedema patients to do to manage the lymphoedema and keep from progressing to more severe stages:

  1. Wash the affected parts twice daily with soap and clean, cool water, and drying carefully
  2. Use medicated creams (antifungal or antibiotics) to treat entry lesions
  3. Wear comfortable shoes
  4. Elevate the affected limb at night
  5. Exercise the limb regularly

**What are the steps in washing the limb once a day with clean water and soap?**

  1. Prepare water, soap, basin, chair, towel and shoes
  2. Wash your hands
  3. Start by washing the healthy leg and then the affected leg
     • Request help from a family member to reach areas that the patient cannot reach.
  4. Place the leg inside the basin
  5. Wet the leg with clean water
  6. Lather your hands with soap and begin washing down the leg, starting from the knee or highest point of swelling
     • Do not use scented soap or wash/dry harshly
  7. Use a towel or your hands (do not use a vegetable sponge or brush)
  8. Wash well between the toes and between skin folds
     • Use a clean soapy strip of cloth and pass it through the toes and folds
  9. Rinse the leg with clean water until the rinse water is clean
 10. Dry the skin well by patting the leg gently with a clean towel
Carefully dry between the toes and skin folds using a small clean towel, swab or cloth.

**How do you treat entry lesions?**
- Concentrate on areas where entry lesions are most common
  - Between the toes
  - In skin folds
  - Around the toenails
- Treatment of lesions between the toes
  - Apply an antibiotic crème
- Treatment of lesions between deep folds
  - Introduce a tissue with potassium permanganate

**What kind of footwear should be worn?**
- Shoes protect the feet from dirt and injury
- Shoes should be adapted to the volume of the feet
- Shoes should not be too tight
- Shoes should not cause wounds

**How do you properly elevate the leg?**
- Sitting:
  - Put the leg on a stool
  - If possible, support the leg with a pillow
  - Rest your back against the chair or the wall
- Lying down:
  - Position legs at a higher elevation than the head
  - Place pillows or bricks under the foot of the mattress or mat
  - Place a pillow underneath the knees to keep the knees slightly bent
How do you exercise the leg?

Three exercises to be practiced as often as possible throughout the day in order to help the lymph circulate:

1. Stand on both feet and maintain balance by holding onto a firm object (person, wall, tree).
   - Slowly lift heels up and rise onto the tips of the toes – briefly holding position before lowering the heels back to the ground.
   - Repeat 10-20 times.

2. While sitting or lying down, point the toes toward the ground, then flex the toes back up.
   - Repeat 10-20 times.

3. While sitting or lying down, point the toes, rotating them in a circular motion, occasionally switching the direction of motion.
Acute Attacks

What are acute attacks?

**Acute attacks = Acute dermato-lymphangio-adenitis (ADL)**

- Bacteria enter through breaks in the skin
- Lymph stasis provides conditions for rapid bacteria growth
- Further damage to small lymphatic vessels
- Cause fibrosis and progression of lymphoedema
What are the symptoms of an acute attack?

- Last ~ 4-7 days
- Painful infections of the skin / superficial tissues
- Symptoms include:
  - Local inflammation
  - Redness of skin
  - Pain or tenderness of skin
  - Swelling
  - Enlargement of lymph node
  - Fever, headache, vomiting

How do you treat an acute attack?

- Patient should be evaluated by a health worker.
- Pain relief is a priority.
  - Paracetamol 500 mg 3x daily
  - Cool limb in a bucket of ice water
- If entry lesions are identified, topical antiseptics or medicated creams should be used.
- Do not do the following:
  - Put the limb in hot water
  - Scratch/cut the skin
  - Burst any blisters
  - Perform exercises
  - Bandage the limb
  - Apply local medicine and herbs

Patient Counselling

- Psychological counselling may be necessary for some lymphoedema patients, especially those with severe disease
- Patients may suffer from shame, isolation, and intense chronic pain and suffering
- If psychological counselling is available, health center staff should know how to refer patients to these services
- Training lymphoedema patients in self care is often helpful in creating hope and decreasing negative feelings
  - Nurses, doctors and community health workers can provide informal counselling as well

**Health Care System**

**Service Delivery Platforms**

- Community-based care
  - Trained patients
  - Trained community caregivers (family members or friends)
  - Trained community health workers
  - Trained health care staff (for supervision)

- Health centers
  - Trained health workers and nurses
  - Drugs for acute attacks

- How to choose the platform?
  - In districts with many lymphoedema cases, community health workers or community caregivers (family members or friends) can be used to monitor patient progress and provide motivation during home visits. Health care staff can be used to supervise these caregivers.
  - In districts with few lymphoedema cases, community caregivers (a family member or friend) can be used to monitor patient progress, help with self-care, and provide motivation. Alternatively, health center staff could manage these patients through home visits or regular patient visits to the health center.
  - In districts with few lymphoedema cases, community health workers can still be used to find patients

**Role of Health Care Workers**

1. Teach the patient self-care skills
   a. Home visits are helpful to ensure necessary supplies and materials are available and patient understands hygiene and exercise instructions (nurses, CHWs)
   b. Sometimes patients cannot visit clinics because their legs are too large or they don’t have transport. In these cases, it can be easier for health center staff to visit patients instead.

2. Manage acute attacks
   a. Patients should be advised to visit health facilities for treatment (doctors, nurses)

3. Assess patient progress
   a. Home visits are useful to encourage self-management, ensure compliance, and troubleshoot problems (nurses, CHWs).
   b. Visits by health care workers can help motivate patients.

4. Report to national level or to district LF focal point
Role of the District NTD Management Team

This role will vary by country, but usually includes the following responsibilities:

1. Oversee district MMDP data.
   a. Liaise with regional/central levels to ensure district data is accurate/updated based on surveys, MMDP implementation activities, etc.
2. Coordinate planning and implementation of situation analysis at district level (see module 6.1).
3. Plan and implement surveys and data collection activities.
   a. Often coordinated with the national programme, this could include burden assessments and/or line listing of cases.
4. Plan and implement training on lymphoedema management for health care workers and patients.
   a. If a national training-of-trainers has taken place, this would involve planning with trainers from the regional level to lead the district-level training. The training of health workers could take place at regional level, combined with other districts.
5. Supervise activities to ensure quality/promote monitoring and evaluation.
6. Report to regional NTD focal point.

Monitoring and evaluating

- Health centers should report to districts every 6 months (or every year) (see reporting form below):
  - Number of lymphoedema patients in health center
  - Number of lymphoedema patients included in activities in previous 6 months
  - Number of visits to lymphoedema patients made in previous 6 months, aggregated by informal caregiver or health staff
  - Number of acute attacks in lymphoedema patients in previous 6 months, aggregated by informal caregiver or health staff

- Districts should report to national level every 6 months (or every year) (see reporting form below):
  - The indicators above, aggregated by health center

- Within two years when the national LF programme submits the LF elimination dossier, district should measure the availability of care
  - Percentage of targeted health facilities providing care for lymphoedema
  - Percentage of targeted health facilities providing care for ADL

- The national LF programme might visit some districts to implement a direct inspection of a health facility to see how care for lymphoedema is being provided.
Coordination and integration

- Lymphoedema management can be integrated with:
  - Other disease specific programs – leprosy, buruli ulcer, podoconiosis, wound care, diabetes
  - Home based care – HIV, chronic diseases

Part 3: Session activities

Activities:

1. Please describe a feasible and appropriate service delivery platform for each example.

   - Example 1. Your district has a population of 400,000; 26 health centers, and 110 lymphoedema cases. Most patients are scattered throughout the district, although there are two villages that each have more than 10 cases.
Example 2. Your district has a population of 150,000 scattered over remote areas; 15 health centers, and 7 lymphoedema cases. It also has a high HIV rate and a strong program of HIV home-based care.

2. If additional time is available, complete the Excel Planning Template for lymphoedema MMDP activities in your district.

Part 4: Summary Job aide

<table>
<thead>
<tr>
<th>Key words (maximum 10)</th>
<th>Key action points for district level personnel</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess burden</td>
<td>Select a method above to assess the number of cases of lymphoedema that exist in your district</td>
</tr>
<tr>
<td>Find suspected cases</td>
<td>Actively find lymphoedema cases by disseminating the message that those with swollen limbs should report to the nearest health center to be registered and treated</td>
</tr>
<tr>
<td>Diagnose cases</td>
<td>Use the images and list of symptoms above to confirm suspected cases of lymphoedema</td>
</tr>
<tr>
<td>Manage lymphoedema</td>
<td>Wash affected parts, use medicated creams, wear comfortable shoes, and elevate and exercise the limb regularly</td>
</tr>
<tr>
<td>Determine service delivery</td>
<td>Determine how community-based care and trained health workers will be utilized to provide care and monitor patient progress</td>
</tr>
<tr>
<td>platform</td>
<td></td>
</tr>
<tr>
<td>Monitor and report</td>
<td>Health centers should report to districts, and districts should report to the national level every 6 months (up to a year)</td>
</tr>
<tr>
<td>Evaluate</td>
<td>District management teams, in coordination with the national programme, can do direct inspection visits to evaluate quality of care.</td>
</tr>
</tbody>
</table>

Part 5: References and Additional Resources

References:

- Lymphatic Filariasis: Managing Morbidity and Preventing Disability: An Aide-Memoire for National Programme Managers (WHO 2013)
  http://apps.who.int/iris/bitstream/10665/85347/1/9789241505291_eng.pdf
- Organizing a Lymphoedema Management Program at the Health District Level (CDC 2010)

**Annexes and additional resources:**

- Training modules on community home-based prevention of disability due to lymphatic filariasis (WHO 2003)
  
  ➢ Learner’s guide:  

  ➢ Tutor’s guide:  

  ➢ Flipchart:  
  [https://www.k4health.org/sites/default/files/WHO%20Lymphatic%20Filariasis%20Flip%20Chart%20Disability%20Prevention--PUBLIC%20DOMAIN_0.pdf](https://www.k4health.org/sites/default/files/WHO%20Lymphatic%20Filariasis%20Flip%20Chart%20Disability%20Prevention--PUBLIC%20DOMAIN_0.pdf)

  ➢ Poster:  

- New Hope for Lymphedema Patients