PALCARE
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THE JIMMY S BILIMORIA FOUNDATION

PALLIATIVE CARE
GUIDELINES
FOR A HOME SETTING IN INDIA

LYMPHOEDEMA

INTRODUCTION

Lymphoedema results from abnormal accumulation of protein-rich fluid in the interstitial spaces due to failure of the lymphatic system to drain fluid from the tissues. This may be primary such as in lymphatic atresia or more commonly, secondary due to damage to lymphatic vessels or nodes.

Lymphoedema is usually unilateral; but when it is bilateral it is usually asymmetrical. Lymphoedema is commonly seen in the extremities but it can occur in the trunk, genitals, head and neck. Chronic lymphoedema is incurable and is managed by daily self-care (skin care, exercises and massage) and lifestyle modification.

The common causes of lymphoedema are:

- Cancer: lymphatic obstruction from direct invasion or nodal involvement
- Treatment
  - Cancer treatment (commonest cause) - radiotherapy, surgery
  - Medications - corticosteroids, non-steroidal anti-inflammatory drugs (NSAIDs)
- Concurrent disease
  - Primary or congenital lymphoedema
  - Cardiac disease
  - Chronic venous insufficiency
  - Trauma
  - Severe infection, filariasis, inflammation
  - Paraparesis, immobility
  - Obesity

ASSESSMENT

- **Assessment** must determine
  - the underlying cause of lymphoedema,
  - effectiveness of treatment and
  - impact on quality of life for the patient and their family (***refer to the Guideline - Symptom Assessment***)
- Assessment of lymphoedema should include a thorough medical history and examination including:
  - Onset and duration
  - Examination of the skin - colour, temperature, breakage, presence of lymphorrhoea
  - Distribution/extent of swelling over extremities, head, neck, trunk, and genital area
  - Circumferential measurement of the limb using tape
  - Palpation of tissues for presence or absence of pitting
  - Associated symptoms - pain, sensory changes, breathlessness, fatigue

- Medications and side effects
- Complications - fungating lesions, lymphorrhoea, infections, brachial plexopathy
- Assess the patient's response to lymphoedema, acceptability and tolerance to treatment modalities, and goals of care

- Assessment of lymphoedema
  - Staging of lymphoedema (https://www.breastcancer.org/treatment/lymphedema/how/stages)
    - Stage 0 (subclinical or latent) - There are no visible changes in the affected area (arm, hand, or upper body, lower limbs); patient may notice a difference in feeling, such as a mild tingling, unusual tiredness, or slight heaviness
    - Stage 1 (mild) - The affected area (arm, hand, trunk, breast, lower limbs or other area) appears mildly oedematous as the protein-rich fluid starts to accumulate; pressing the skin leaves a temporary small dent (or pit)
    - Stage 2 (moderate) - The affected area is even more oedematous with non-pitting swelling; there are changes to the tissue under the skin such as inflammation, hardening, or thickening
    - Stage 3 (severe) - The affected extremity or area of the body becomes very large and deformed, and the skin takes on a leathery, wrinkled appearance
  - Stemmers sign
    Attempt to pinch and lift skinfold at the base of the second toe (or middle finger)
    - The test is negative if you are able to pinch skin and positive if you are unable to pinch skin
      - Positive - lymphoedema
      - Negative - does not rule out lymphoedema but imply other causes of swelling
        - Absence of swelling at base of digit - suggestive of chronic venous Insufficiency
        - Presence of pitting swelling of the base of digit: suggestive of CCF, nephrotic syndrome, cirrhosis, etc.

- Assessment of skin changes in lymphoedema
  - Skin thickening
  - Lymphangiectasis
  - Papillomata
  - Redness and other signs of inflammation/infection
  - Lymphorrhoea

- Assessment of psycho-social aspects
  - Worsening level of functional ability, independence, dignity
  - Changes in social position, relationships
  - Concern about income, job
  - Changes and concern about body image
  - Concern about ill-fitting clothes and shoes

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RECOMMENDATION

- Early diagnosis and proactive treatment are key to prevent progress of lymphedema and complications
- Multi-disciplinary team approach with involvement of nurse, palliative care physician, oncologist, lymphoedema therapist etc. should be encouraged
- Family and caregivers should be involved in the simple physical techniques involved in the treatment of lymphoedema, when possible and necessary
- Regularly reassess for the benefits, risks and burden of the treatments
- Regularly reassess the clinical status and contraindications for the modalities of treatment involved
- When developing a structured exercise programme, be cognisant of the risk of pain, pathologic fracture, breathlessness, and fatigue
- Multi-layer bandaging is recommended in the initial stage of the management of lymphoedema of the extremities
- Multi-layer bandaging is recommended in the management of lymphoedema associated with broken, ulcerated and fragile skin, and lymphorrhoea
- Elastic compression garments are recommended in the long-term management of lymphoedema of the extremities, when the swelling has stabilised
- Manual lymphatic drainage is recommended in the management of lymphoedema of breast, trunk, genital, head and neck, and the base of the extremity
- Manual lymphatic drainage is contraindicated in cellulitis, renal failure, hypertension, SVC obstruction, and around primary and secondary tumours

MANAGEMENT

Definitive treatment - Definitive treatment should be considered after taking into account the likely prognosis

- Debulking surgery - to reduce the tumour bulk
- Systemic therapy - chemotherapy, hormone or targeted therapy – to reduce the tumour bulk
- Lympho-venous anastomosis - restoration of lymphatic flow

Correct the correctable - As lymphoedema could be co-existing with potential reversible factors contributing to fluid retention or venous congestion, treatment of the potentially reversible factors should be considered. The potential reversible factors and their treatments are:

- Anaemia - blood transfusion
- Ascites - ***refer to the Guideline - Ascites***
- SVC obstruction - ***refer to the Guideline - SVC Obstruction***
- Inferior vena-cava obstruction - corticosteroids, stent insertion
- Medications e.g., corticosteroids, non-steroidal anti-inflammatory drugs (NSAIDs) - stop the medications

Non-pharmacological measures - Decongestive lymphatic therapy (DLT) is a combination of manual lymphatic drainage, compression bandaging, exercise and skin care

- Skin Care - ***refer to Skin care in the Guideline - Wound Care***
  - Keep skin moist and supple - use low pH emollients/lotions
  - Wipe dry the webspace between the fingers and toes to avoid fungal infections
  - Protect the swollen extremities from the sun by being in the shade or applying high factor sunblock products
  - Avoid wearing tight-fitting garments/shoes/jewels
  - Use clippers to clip the nails; avoid scissors
  - In upper extremity lympheodema:
    - Protect the hands with mittens/gloves to avoid injuries
    - Use a thimble when sewing
    - Be careful when gardening e.g. pruning roses
  - In lower extremity lympheodema
    - Wear footwear to avoid injuries
  - If there is any injury the area to the swollen areas, wash the area thoroughly and use an antiseptic
  - Use insect repellents to prevent insect bites
  - If bitten by insect, then use an antiseptic and/or anti-histamines
  - Avoid the following on the swollen extremity:
    - Administration of injections or parenteral fluids
    - Measurement of blood pressure
    - Blood being drawn
  - Carry adequate supply of high factor sun block products, insect repellents, antiseptic solutions, antihistamine tablets and appropriate antibiotics (if there is history of recurrent infections)
- Extremity positioning and supporting
  - Elevate the swollen extremity above the level of heart to reduce the swelling by promoting venous drainage and decreasing the lymphatic pressure
  - Elevate the swollen extremity while sitting, to reduce dependency to reduce the risk of lymphoedema
  - Support a paralysed extremity with a Lancaster sling
- Exercise
  - Participate in activities of daily living to improve lymphatic flow (muscle pump)
  - If the patient is able to, start a structured exercise programme as described below:
    - Introduce a general exercise programme which includes active range of motion exercise of the joints
    - Start a low to moderate intensity exercise programme; walking, swimming, cycling and low impact aerobics
    - Compression garments should be worn during the exercises
    - Warming up and cooling down should be part of the exercise programme
  - Structured training programme
    - Lower limb
      - Patient should be sitting in upright position

- The affected limb should be well supported along the entire length during the exercise programme
- Flex the toes fully and hold for 5 seconds; then release. Repeat twenty times
- Extend the toes fully and hold for 5 seconds; then release. Repeat the procedure twenty times
- Rotate the foot in clockwise direction slowly at the ankle level and complete twenty circles; repeat the same motion in anticlockwise direction and complete twenty circles
- Extend the foot fully and hold for 5 seconds; then release. Repeat twenty times
- Flex the foot fully and hold for 5 seconds; then release. Repeat 20 times
- Raise the affected leg up and hold straight for 5 seconds; repeat ten times
- Stand on the toes with the palms gently resting on a table for support and hold for 5 seconds; then release. Repeat twenty times

❖ Upper limb

- The affected limb should be well supported on a pillow at the shoulder level along the entire length during the exercise programme
- Curl the fingers to make a tight fist and hold for 5 seconds; then release. Repeat twenty times
- Extend the fingers fully and hold for 5 seconds; then release. Repeat twenty times
- Extend the hand fully at the wrist level keeping the fingers straight and hold for 5 seconds; then release. Repeat twenty times
- Flex the hand fully at the wrist level keeping the fingers straight and hold for 5 seconds; then release. Repeat twenty times
- Rotate the hand at the wrist clockwise at the wrist level slowly and complete twenty circles; repeat the same motion in anticlockwise direction and complete twenty circles
- Flex the forearm at the elbow level keeping the fingers straight and make a tight fist when the forearm is fully flexed; hold for five seconds and then release. Repeat twenty times

- Compression
  - ➢ Multi-layer lymphoedema bandaging
    - ❖ Series of layers of inelastic or low stretch bandages are applied to the swollen extremity from the distal end to the proximal, creating a graduated compression decreasing from the distal area to the proximal area
    - ❖ Compression bandage has to be applied by a trained healthcare professional
  - ➢ Elastic compression garments
    - ❖ A proper fitting elastic compression garment is necessary
    - ❖ An ill-fitting compression garment would lead to development of swelling distal or proximal to the garment

- Patient should be reassessed 6 weeks after the first fitting and every 3 - 6 months, thereafter
- Elastic compression garment should be removed if there is pain, numbness or cramps and the patient should be referred to a lymphoedema specialist
- Elastic compression bandage should be washed every time after being used and replaced every 3 - 6 months or earlier if it is worn out

- Massage techniques
  - Manual lymphatic drainage (MLD)
    - MLD is to be performed by a trained professional
    - MLD is usually combined with other treatment techniques, especially compression
    - MLD can be used in advanced cancer with metastasis, if benefits outweigh the risks and if patient gives informed consent
  - Simple lymphatic drainage
    - Simple lymphatic drainage is based upon MLD
    - It can be taught to the patient and carers to perform at home
    - Patient/carer should apply simple lymphatic drainage daily

Pharmacological measures

- Corticosteroids
  - Dexamethasone 6mg bd/24 hours for one week
  - If effective after one week, then titrate downward to the minimum effective dose
  - If ineffective after one week, stop immediately

Management of complications

- Cellulitis
  - Amoxycillin 500mg PO q8h or erythromycin 500mg PO q6h (if patient is allergic to penicillin)
  - Clindamycin 300mg PO q6h - if cellulitis is not responding adequately to amoxycillin after 48 hours
  - Flucloxacillin 500mg PO q6h is to be added if staphylococcal infection is suspected
  - Antibiotics should be continued for 2 weeks or until signs of inflammation resolve
- Lymphorrhoea
  - MLD with absorbent padding should be used
  - Change the bandage as and when the leakage breaks through the padding

REFERENCES

EpoMedicine. Edema – Physical Examination. Retrieved online from http://epomedicine.com/clinical-medicine/physical-examination-edema/ on 11 March 2019

Fu, M.R., and Lasinski, B.B. (2015). Lymphoedema Management. Oxford Textbook of Palliative Nursing. (pp. 279-296)

Hewitt, B., Bugden E., and Levinson, P. Lymphoedema Management in Palliative Care. *Cancer Forum* (2010); 34(2): 1-3

International Lymphoedema Framework. The Management of Lymphoedema in Advanced Cancer and Oedema at the End of Life. Retrieved online from https://www.lympho.org/wp-content/uploads/2016/03/Palliative-Document.pdf on 11 March 2019

Keeley, V. (2015). Lymphoedema. Oxford Textbook of Palliative Medicine. (pp. 740-746)

The Lymphoedema Support Network. Oedema in advanced ill health. Retrieved online from https://www.lymphoedema.org/index.php/information-for-health-care-professionals/managing-oedema-in-advanced-ill-health on 11 March 2019

Towers, A., and Hodgson, P. (2012). Lymphoedema. Palliative Medicine – A Case-Based Manual. (pp. 301-313)

Towers, A., Hodgson, P., Shay, C., and Keeley, V. Care of Palliative Patients with Cancer-related Lymphoedema. *Journal of Lymphoedema* (2010); 5(1): 72-80

Twycross, R. (2003). Secondary symptoms. Symptom Management II. Introducing Palliative Care. (pp. 144-149)