Expanding Lymphedema Prevention and Management Programs in Rural Health and Third World Countries: A Capstone Presentation

By: Cally Tejkl
Pacific University
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Objectives

- Define lymphedema
- Explain current evidence based treatment interventions to manage the symptoms of lymphedema
- Explore current access issues to appropriate treatment interventions
- Discuss development and implementation of a lymphedema program in a rural healthcare setting including a post-mastectomy component
- Discuss development of an educational program for Haitian healthcare workers to work towards eradication of lymphatic filariasis

What is lymphedema?

- Lymphedema is characterized by the "accumulation of protein-rich fluid within the interstitial spaces, often leading to the chronic inflammation and reactive fibrosis in the affected tissues" (Foldi, Foldi, & Kubik, 2003, p. 53).
- Lymphedema can be located in one or multiple extremities, the trunk, abdomen, head and neck, external genitalia, and internal organs (Zuther & Norton, 2013).

Incidence Rates

- Lymphedema affects at least 3 million Americans (Quirion, 2010; Zuther & Norton, 2013)
- Estimated that more than 11.4 million cancer survivors in the United States are at risk for developing this serious condition (Armer et al., 2012)
- Among 120 million people in 83 countries that are infected with lymphatic filariasis, up to 16 million have lymphedema (Shenoy, 2008).

Primary vs. Secondary Lymphema

Primary

- Occurs due to a developmental abnormality of the lymphatic system that may be present at birth or develop later in life (Zuther & Norton, 2013).

Secondary

- Caused by surgery and radiation, trauma, infection, malignant tumor, immobility, and chronic venous insufficiency (Zuther & Norton, 2013).
- May occur immediately postoperative, within a few months, a couple of years, or even 20 years or more following surgery

Stages

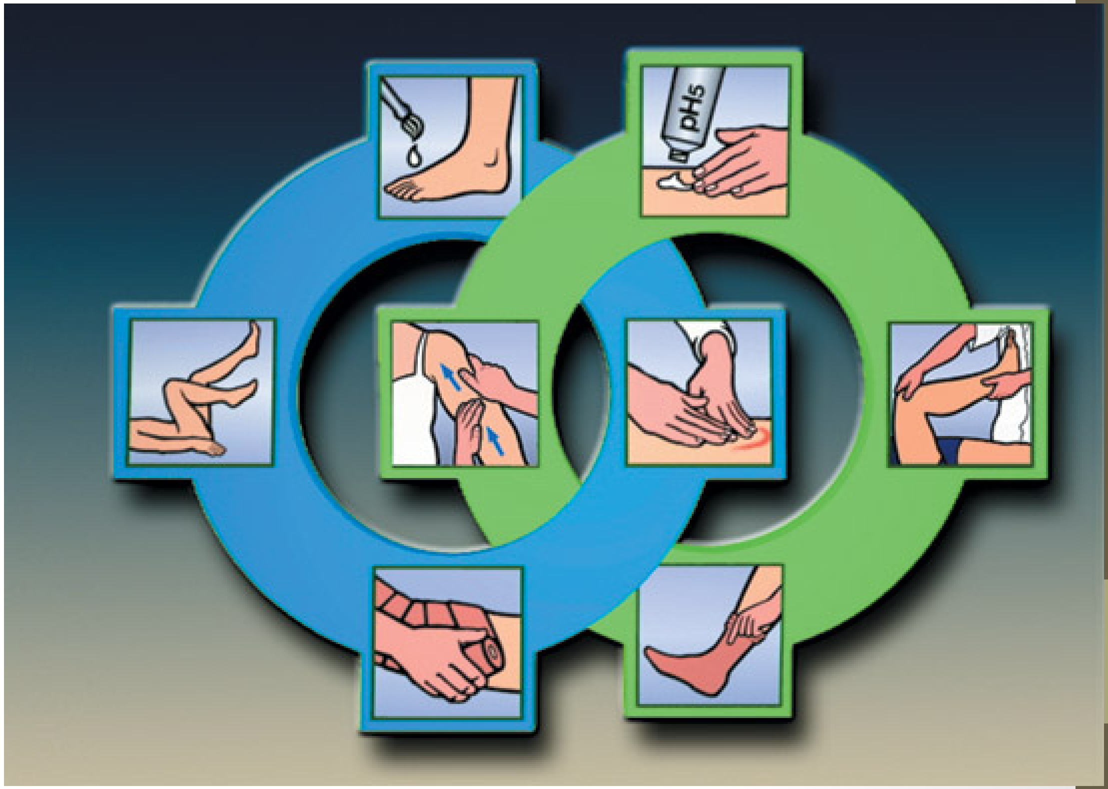
- Stage 0 is known as subclinical or pre-lymphedema, can last for a long time, and typically includes all patients who have had lymph node dissection. During this stage there is no swelling present, however lymph flow is impaired.
- Stage I is characterized by accumulation of fluid and protein in the tissue in which pitting may be present. Elevation may reduce the swelling in this stage.
- Stage II includes swelling that does not reduce with elevation and pitting occurs with fibrosis.
- Stage III is characterized by fibrotic tissue that has indiscernible pitting, skin thickening, and large limb volume known as elephantiasis (International Society of Lymphology, 2003).

Treatment

- No cure
- Complete Decongestive Therapy (CDT)
- Two phases
  1. Intensive Phase
  2. Self-management Phase

Complete Decongestive Therapy (CDT)

- Manual Lymph Drainage
- Compression Therapy
- Therapeutic Exercise
- Skin Care



Manual Lymph Drainage

- Goal: Decrease size of affected area
- Gentle manual treatment technique that increases the activity of certain lymph vessels and manually moves interstitial fluid
- Reroutes lymphatic load around damaged or blocked pathways and utilizes undamaged pathways
- Massage vs. MLD

Compression Bandaging

- In order to prevent the swelling from coming back, it is necessary to apply sufficient compression to the arm or leg.
- Intensive phase: Application of special short-stretch bandages to prevent the re-accumulation of lymph fluid.

Compression Bandaging – Cont.

- Self-management phase: Once the extremity is decongested, the patient wears compression garments during the day.

Therapeutic Exercise

- A customized exercise program is designed for each patient in order to assist in the decongestive process by stimulating the lymphatic system (promoting reabsorption).

Skin Care

- The skin of individuals with lymphedema is extremely dry and susceptible to infections.
- Goals:
  - Avoid bacterial and fungal growth
  - Avoid infections
  - Supply moisture to the dry skin
  - Wound care

Access Issues

Barriers

- Lack of medical knowledge and expertise in the diagnosis and treatment
- Geographic barriers
- Focus on secondary care setting
- Time and cost for certification of therapist
- Cost of starting lymphedema program

Lymphedema Program Development – Rural Healthcare

- **Purpose:** The purpose of this project is to improve access to appropriate treatment interventions to those with lymphedema in a rural area.

- **Goal:** The goal of this project is to help improve individuals' overall quality of life, functional abilities, and psychological deficits through education and implementation of CDT with aims to combat lymphedema and improve the lives of those suffering.

Rural Program Development

- Literature Review
- CLT Certification – ACOLS.org
- Development of Therapist Documentation Materials*
- Development of Patient Education Materials *
- Production of Lymphedema Program Environment
- Hospital Staff Education
- Public Education/Marketing
- Post-Mastectomy Program Development

Post-Mastectomy Program Development

- In the United States, the most common cause of lymphedema develops in the upper extremity following axillary node dissection due to breast cancer and subsequent surgical intervention.

- The National Surgical Adjuvant Breast and Bowel Project (NSABP) B-04 trial documented rates of breast cancer related lymphedema (BCRL) of 58.1%, 38.2%, and 49.1% for radical mastectomy, total mastectomy with axillary radiation, and total mastectomy.

Post-Mastectomy Program Development

- **Purpose:** The purpose of this project is to improve post-surgical care for those receiving mastectomies in a rural hospital setting.

- **Goal:** The goal of this project is to help improve individuals' overall quality of life, functional abilities, and psychological deficits through education and individualized exercise program development. A second goal was to educate on lymphedema and preventative techniques to reduce incidence of development of lymphedema.

Post-Mastectomy Program Development

- Literature Review
- Collaboration with Med Staff and surgical team
- Development of Patient Education Materials
- Hospital staff education

Post-Mastectomy Program

- Surgical Day: Introduction of therapist to patient as inpatient
- 3 Day P/O: Evaluation, education, and exercise (with HEP set up)
- 7 Day P/O: Exercise advancement
- 3 Week P/O: Exercise advancement
- 6 Week P/O: Exercise advancement and discharge if goals met

Post-Mastectomy Program Outcomes

- 3 Post-Mastectomy Patients have been seen within the rehabilitation department; 3/3 came to 100% of therapy sessions; 90% goal attainment;

- Future Plans:

  - Continued Collaboration
  - Marketing Strategies

Lymphedema in Third World Countries

- Lymphatic Filariasis
- Second leading cause of chronic disability worldwide
- Mosquito transmission
- Treatment

Elephantiasis of the legs due to filariasis (CDC).

Lymphatic Filariasis

- Barriers – Extreme poverty, quality of environmental surroundings, decreased educational levels, lack of quality healthcare organizations
- Global Programme to Eliminate Lymphatic Filariasis (GPELF)
- Mass drug administration
- Solutions

Lymphedema Teaching Plan for Haitian Healthcare Workers

- **Purpose:** The purpose of the teaching plan is to improve the knowledge of the medical professionals of Haiti about lymphatic filariasis with hopes of combating this disease and improving the lives of those suffering.
- **Goal:** The goal of this project is to help individuals' overall quality of life, functional abilities, and psychological deficits through education and intervention about lymphedema. Although there is no cure for this disease, with appropriate education and supplies, the limb or area of swelling can be significantly reduced.

Lymphedema Teaching Plan

- Mission of Hope Haiti
- Development of Educational Materials

Teaching Plan Objectives

1. "Teach back" of educational handouts
2. Correct MLD sequence completed following demonstration
3. Correct application of compression bandaging following demonstration

Content Outline

- **Introduction:** Purpose of project, overview of content
- **Body:** Lymphedema overview, simple anatomy/physiology of systems involved, causes, treatment interventions, prevention, pharmacological interventions, CDT components
- **Hands on Lab:** MLD, Compression bandaging, garment measuring
- **Conclusion:** Compliance to Pharmacological interventions and CDT; Promotion of Self-management

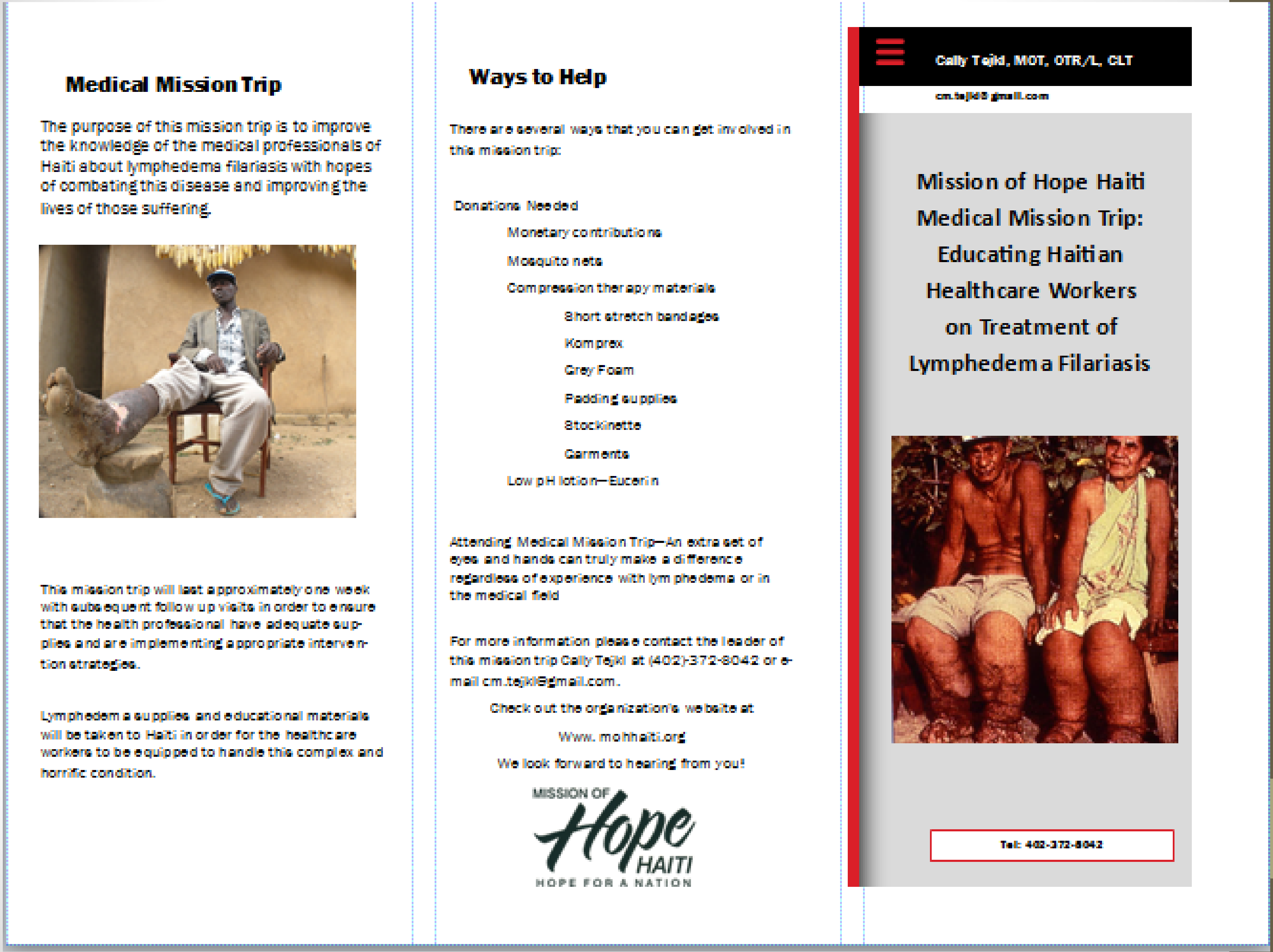
Methods of Instruction/Resources

- Lymphedema training packet
- Lecture
- Hands-on opportunities

Evaluation of learning: Survey

Fundraising Materials

- Monetary
- Compression bandaging materials
- Garments



Medical Mission Trip

The purpose of this mission trip is to improve the knowledge of the medical professionals of Haiti about lymphedema filariasis with hopes of combating this disease and improving the lives of those suffering.

This mission trip will last approximately one week with subsequent follow up visits in order to ensure that the health professional have adequate supplies and are implementing appropriate intervention strategies.

Lymphedema supplies and educational materials will be taken to Haiti in order for the healthcare workers to be equipped to handle this complex and horrific condition.

Ways to Help

There are several ways that you can get involved in this mission trip:

Donations Needed
- Monetary contributions
- Mosquito nets
- Compression therapy materials
  - Short stretch bandages
  - Komprex
  - Grey Foam
  - Padding supplies
  - Stockinette
  - Garments
- Low pH lotion—Eucerin

Attending Medical Mission Trip—An extra set of eyes and hands can truly make a difference regardless of experience with lymphedema or in the medical field

For more information please contact the leader of this mission trip Cally Tejkl at (402)-372-8042 or e-mail cm.tejkl@gmail.com.

Check out the organization's website at

Www. mohhaiti.org

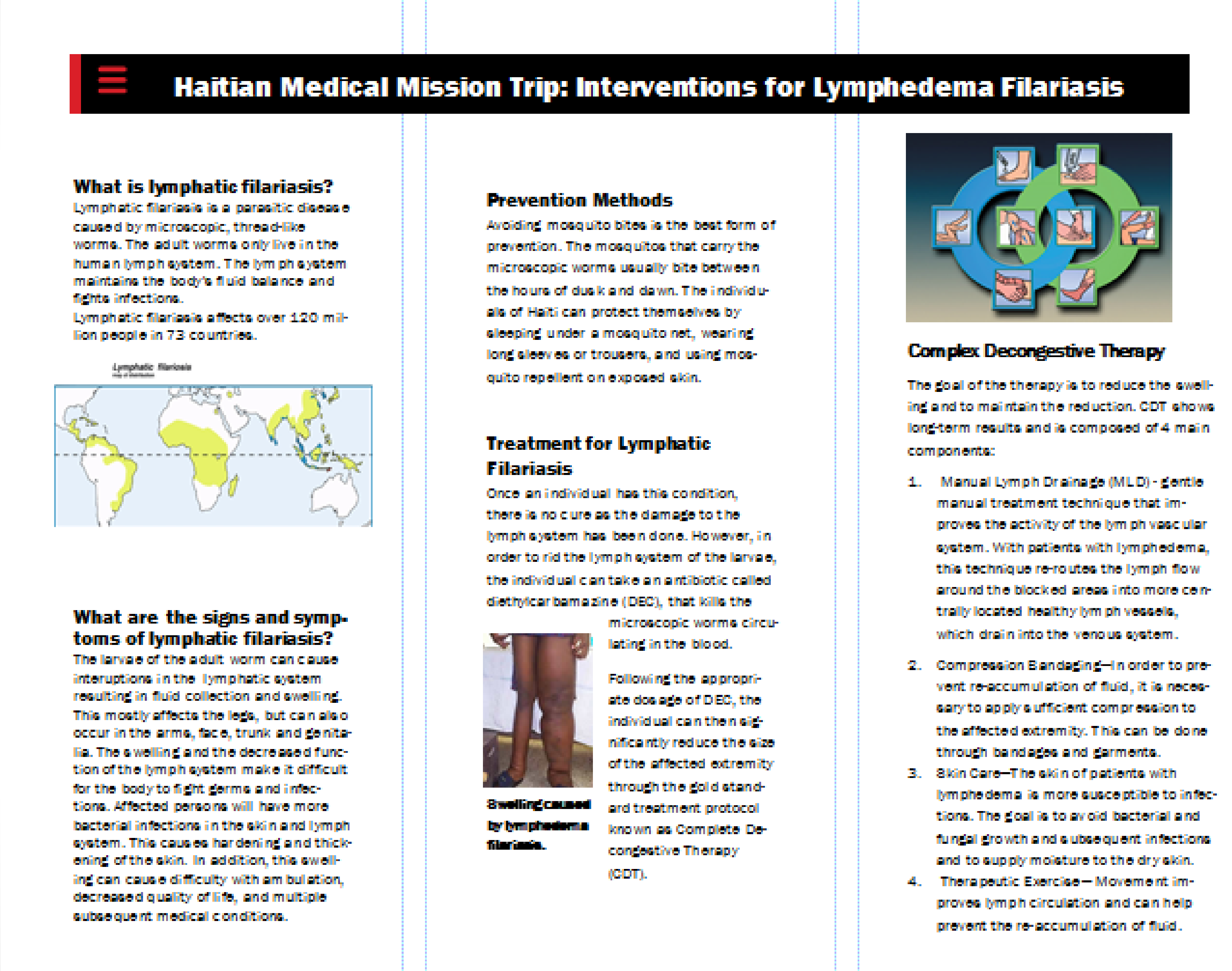
We look forward to hearing from you!

MISSION OF Hope HAITI
HOPE FOR A NATION

Cally Tejkl, MOT, OTR/L, CLT
cm.tejkl@gmail.com

Mission of Hope Haiti Medical Mission Trip: Educating Haitian Healthcare Workers on Treatment of Lymphedema Filariasis

Tel: 402-372-8042



Haitian Medical Mission Trip: Interventions for Lymphedema Filariasis

What is lymphatic filariasis?

Lymphatic filariasis is a parasitic disease caused by microscopic, thread-like worms. The adult worms only live in the human lymph system. The lymph system maintains the body's fluid balance and fights infections.

Lymphatic filariasis affects over 120 million people in 73 countries.

Lymphatic filariasis

What are the signs and symptoms of lymphatic filariasis?

The larvae of the adult worm can cause interuptions in the lymphatic system resulting in fluid collection and swelling. This mostly affects the legs, but can also occur in the arms, face, trunk and genitalia. The swelling and the decreased function of the lymph system make it difficult for the body to fight germs and infections. Affected persons will have more bacterial infections in the skin and lymph system. This causes hardening and thickening of the skin. In addition, this swelling can cause difficulty with ambulation, decreased quality of life, and multiple subsequent medical conditions.

Prevention Methods

Avoiding mosquito bites is the best form of prevention. The mosquitos that carry the microscopic worms usually bite between the hours of dusk and dawn. The individuals of Haiti can protect themselves by sleeping under a mosquito net, wearing long sleeves or trousers, and using mosquito repellent on exposed skin.

Treatment for Lymphatic Filariasis

Once an individual has this condition, there is no cure as the damage to the lymph system has been done. However, in order to rid the lymph system of the larvae, the individual can take an antibiotic called diethylcarbamazine (DEC), that kills the microscopic worms circulating in the blood.

Swelling caused by lymphedema filariasis.

Following the appropriate dosage of DEC, the individual can then significantly reduce the size of the affected extremity through the gold standard treatment protocol known as Complete Decongestive Therapy (CDT).

Complex Decongestive Therapy

The goal of the therapy is to reduce the swelling and to maintain the reduction. CDT shows long-term results and is composed of 4 main components:

1. Manual Lymph Drainage (MLD) - gentle manual treatment technique that improves the activity of the lymph vascular system. With patients with lymphedema, this technique re-routes the lymph flow around the blocked areas into more centrally located healthy lymph vessels, which drain into the venous system.
2. Compression Bandaging—In order to prevent re-accumulation of fluid, it is necessary to apply sufficient compression to the affected extremity. This can be done through bandages and garments.
3. Skin Care—The skin of patients with lymphedema is more susceptible to infections. The goal is to avoid bacterial and fungal growth and subsequent infections and to supply moisture to the dry skin.
4. Therapeutic Exercise— Movement improves lymph circulation and can help prevent the re-accumulation of fluid.

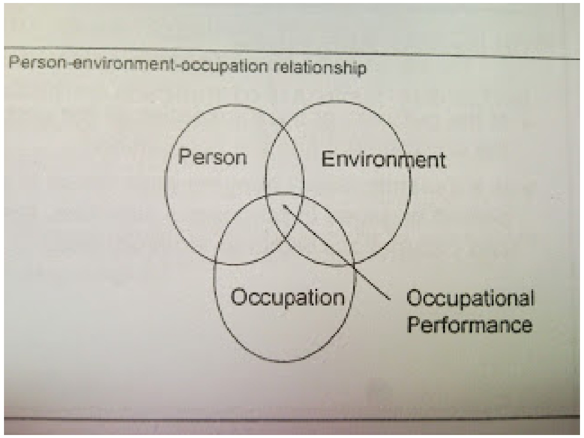
OT and Lymphedema

Framework

The goal of this project is to help individuals' overall quality of life, functional abilities, and psychological deficits through education and intervention about lymphedema.

Biomechanical Approach

Person-Environment-Occupation-Performance (PEOP)



References

Ahmed, R. L., Prizmen, A., Laxocich, D., Schmitz, K. H., & Folson, A. R. (2008). Lymphedema and quality of life in breast cancer survivors: The Iowa women's health study. *Journal of Clinical Oncology, 24*(18), 5689-5695.

Armer, J. M., Stewart, B. R., Wanchai, A., Lasinski, B. B., Smith, K. M., & Cormier, J. N. (2012). Rehabilitation concepts among aging survivors living with and at risk for lymphedema. *Topics in Geriatric Rehabilitation*, *28*(4), 260-268. doi:http://dx.doi.org.proxy.lib.pacificu.edu:2048/10.1097/TGR.0b013e318256cf44

Beaulac, S. M., McNair, L. A., Scott, T. E., LaMorte, W. W., & Kavanah, M. T. (2002). Lymphedema and quality of life in survivors of early-stage breast cancer. *Archives of Surgery, 137,* 1253-1257.

Carreon, D. & Noymer, A. (n.d.) Aging and health for racial minorities: An analysis of the double jeopardy hypothesis using the California health interview survey. *University of California,* 1-15.

Coulborn, A., & Hampton, S. (2012). Understanding assessment and management of lymphoedema. *Nursing & Residential Care*, *14*(10), 516-520.

Doherty, D. (2006). Lymphoedema diagnosis and management. *Wound Essentials 1*, 156-65.

Emmel, N. & Conn, C. (2004). *Towards community involvement.* Leeds, U.K.: Nuffield Institute for Health, University of Leeds.

Foldi, M., Foldi, E., & Kubik, S. (2003). *Textbook of lymphology: For physicians and lymphedema therapists.* San Francisco, CA: Urban and Fisher.

Green, T. (2010) Key-worker clinics: The maintenance phase of lymphoedema therapy. *Chronic Oedema, 15*(10), 17-21.

References – Cont.

International Society of Lymphology. (2003). The diagnosis and treatment of lymphedema. Consensus document of the International Society of Lymphology. *Lymphology, 36*(2), 85-86.

Jordan, K. (2013). *Clarke honored by the Carter Center.* Retrieved from http://abclocal.go.com/wls/story?section=news%2Flocal&id=9241983

Kwan, W., Jackson, J., Weir, L. M., Dingee, C., McGregor, G., & Olivotto, I. A. (2002). Chronic arm morbidity after curative breast cancer treatment: Prevalence and impact on quality of life. *Journal of Clinical Oncology, 20*(20), 4242-4248.

Mak, S., Mo, K., Suen, J., Chan, S., Ma, W., & Yeo, W. (2009). Lymphedema and quality of life in Chinese women after treatment for breast cancer. *European Journal Of Oncology Nursing*, *13*(2), 110-115. doi:http://dx.doi.org.proxy.lib.pacificu.edu:2048/10.1016/j.ejon.2009.01.005

Mass Drug Administration for the Elimination of Lymphatic Filariasis - Port-au-Prince, Haiti, 2011-2012. (2013). *MMWR: Morbidity & Mortality Weekly Report*, *62*, 466-468.

Moffatt, C. J., Franks, P. J., & Doherty, D. C. (2003). Lymphoedema: An underestimated health problem. *Quality Journal of Medicine, 96*(10), 731-738.

National Lymphedema Network. (2010). *Position statement of the National Lymphedema Network: Training of lymphedema therapists.* Retrieved February 11, 2013, from http://www.lymphnet.org/pdfDocs/nlntraining.pdf

National Lymphedema Network. (2011). *Position statement of the National Lymphedema Network: The diagnosis and treatment of lymphedema.* Retrieved February 11, 2013, from http://www.lymphnet.org/pdfDocs/nlntreatment.pdf.

References – Cont.

Poage, E., Singer, M., Armer, J., Poundall, M., & Shellabarger, M. (2008). Demystifying lymphedema: Development of the lymphedema putting evidence into practice card. *Clinical Journal Of Oncology Nursing*, *12*(6), 951-964. doi:http://dx.doi.org.proxy.lib.pacificu.edu:2048/10.1188/08.CJON.951-964

Ridner, J. M. (2009). Fluid transport gone wrong: An introduction to lymphedema. *Journal of Advanced Nursing, 17*(29), 322.

Quirion, E. (2010). Recognizing and treating upper extremity lymphedema in postmastectomy/lumpectomy patients: A guide for primary care providers. *Journal Of The American Academy of Nurse Practitioners*, *22*(9), 450-459. doi:http://dx.doi.org.proxy.lib.pacificu.edu:2048/10.1111/j.1745-7599.2010.00542.x

Shenoy, R. K. (2008). Clinical and pathological aspects of filarial lymphedema and its management. *Korean Journal of Parasitol, 46*, 119-125.

Weiss, J. M. & Spray, B. J. (2002). The effects of complete decongestive therapy on quality of life of patients with peripheral lymphedema. *Lymphology, 35*(2), 46-58.

World Health Organization. (2013). Global programme to eliminate lymphatic filariasis: progress report for 2012. *Weekly Epidemiological Record*, *88*, 389-399.

Zuther, J. E. & Norton, S. (2013). *Lymphedema management.* New York, NY: Thieme Medical Publishing Group.

Questions?