



COLUMN EDITOR: PATRICIA DICKSON

The occupational therapist's role in lymphedema self-management

Byron Shier

Lymphedema is a chronic medical condition caused by an abnormal accumulation of protein-rich lymphatic fluid in the extra-vascular (interstitial) space, causing recurrent or progressive swelling associated with physical, psychosocial, and occupational performance complaints (Ramos, O'Donnell, & Knight, 1999; Woods, Tobin, & Mortimer, 1995). Lymphedema onset is associated with a variety of medical diagnoses including venous disease, infection, and oncological, orthopedic and congenital issues. Occupational therapy services are indicated to assist clients to concurrently address integration of lymphedema self-management techniques into daily living and any occupational performance complaints associated with lymphedema onset. Occupational therapists can enhance their professional practice by pursuing continuing education opportunities to develop specialized clinical skills in lymphedema assessment and treatment.

This article will discuss various issues facing the client with lymphedema, and the role of the occupational therapist in dealing with those issues. It will also briefly describe complete decongestive therapy (CDT), a widely accepted treatment protocol, which integrates client self-management as a key component of treatment interventions (Executive Committee of International Society of Lymphology, 2009).

Reduced independence

Chronic lymphedema may contribute to clients developing physical impairments including mobility restrictions and orthopedic or soft tissue issues. Impaired client strength, endurance, dexterity, and mobility may contribute to functional performance complaints (Crane, 2009; Helms, Kuhn, Moser, Rummel, & Kreienberg, 2009). Physical complaints may impede our clients' ability to complete lymphedema self-management strategies including: ability to don and doff graduated compression garments, routine self-bandaging, and skin care. The occupational therapist's skill in activity analysis will facilitate addressing these challenges by introducing adaptive strategies, equipment and biomechanical education to promote client independence. The occupational therapist's ability to successfully address these functional issues may be the difference between our clients' success in managing their lymphedema independently versus having to rely on daily caregiver assistance.

Clients' effective self-management may contribute to a reduction in secondary complications including the risk of serious infection requiring emergency department visits or hospitalization (Williams, Franks, & Moffatt, 2005). Ko, Lerner, Klose, and Kosimi (1998) found that incidence of infections decreased from 1.10 infections per patient per year to 0.65 infections per patient per year after a course of intensive therapy followed by consistent client self-management. The occupational therapist needs to consider assessing clients' abilities with bathing, skin care, wound care, and appropriately donning and doffing fitted graduated compression garments. The occupational therapist may provide client and caregiver education on the signs and symptoms of infection and the importance of immediate medical follow-up. Furthermore, occupational therapists may incorporate client-appropriate adapted strategies to enable improved occupational performance. Occupational therapists may also be involved in homecare coordination, including assessing a client's caregiver needs.

Psychological issues

Research suggests lymphedema onset poses a significant risk of psychological morbidity with clients' ability to engage in meaningful, purposeful, activities of daily living. McWayne and Heiney (2005) report onset of lymphedema contributes to frustration, distress, depression and anxiety, subsequently contributing to impaired occupational performance. This study notes clients also report becoming angry with perceived loss of independence with leisure and vocational pursuits. Occupational therapists have a role to provide education and intervention, and coordinate appropriate referrals to other health disciplines in order to improve clients' psychosocial status and support improved functional performance.

Occupational performance barriers

The focus of occupational therapy is to enable occupation by holistically addressing occupational performance barriers. Evidence suggests clients with lymphedema often report declines in at least one area of occupational performance. McWayne and Heiney (2005) report some clients with lymphedema have noted difficulties in performance of basic self-care activities including dressing and bathing. In clinical



Client with lymphedema prior to complete decongestive therapy.

practice, clients often report difficulty fitting clothes due to volume changes of their affected limbs. This was one concern reported by a secondary lymphedema breast cancer survivor as seen in the pre and post treatment photographs (see above).

Radina and Armer (2001) report clients have modified routine home management tasks to reduce noticeable flare-up of symptoms, while Ridner (2009) reports clients with lymphedema may reduce their social and leisure activities. In clinical practice, clients have reported flare-up of symptoms after homemaking, cleaning and vacuuming tasks, and leisure and social activities including golfing, playing with children/grandchildren, knitting, or utilizing a home computer. Lymphedema clients may experience a negative impact on their vocational pursuits as well. Soran and colleagues (2006) found that the level of hand use based on vocational requirements was a statistically significant risk factor in lymphedema onset. Return to work concerns cited by clients in clinical practice include decreased workplace durability, an increase in lymphedema-related pain symptoms, and perceived limb volume increases while at work. Completion of a worksite ergonomic and job demands analysis provides opportunity to address workplace set-up, work conditioning, and work behaviors to support a durable return to work. A review of this author's clinical practice outcomes in 2008 suggests 60% of clients assessed by the occupational therapist identified at least one occupational performance complaint associated with lymphedema onset. As research and clinical evidence suggests lymphedema clients routinely experience occupational performance deficits, occupational therapists have a role to help clients meet these challenges.

Complete decongestive therapy (CDT)

Complete decongestive therapy (CDT) is a widely accepted



Client with lymphedema after complete decongestive therapy.

treatment protocol, which integrates client self-management as a key component of treatment interventions (Executive Committee of International Society of Lymphology, 2009). Lymphedema clients may present with absolute and relative medical contraindications that must be recognized by the assessing clinician. Training to learn CDT techniques will provide occupational therapists with an opportunity to acquire condition-specific assessment and treatment skills that are fundamentally important to guiding appropriate clinical care, judgment, and decision-making. By enhancing their practice knowledge and skills in this area, occupational therapists will be able to provide more effective treatment services for clients.

One important component of CDT is integrating client self-management education into treatment sessions. Vignes, Porcher, Arrault, and Dupuy (2007) comment on the importance of effective client self-management, finding clients' compliance with routine use of graduated compression garments and low stretch self-bandaging of the affected limb is crucial to stabilize lymphedema volume over time. Lymphedema clients report challenges implementing these required self-care management strategies including mobility restrictions, location of lymphedema, and the daily time required to complete care (Mayrovitz, 2009). Clients who effectively integrate self-management strategies may help expedite the rehabilitative process, improve clinical outcomes, and reduce the frequency of required follow-up services with a health care professional to address lymphedema-related concerns. Cheville, McGarvey, Petrek, Russo, Taylor, and Thiadens (2003) provide an outline of conventional CDT treatment: a multi-modal, two-phase approach to lymphedema management. The first phase includes up to daily treatment sessions involving a combination of manual lymphatic drainage techniques, multi-layered graduated compression bandaging, skin care, and a remedial exercise

program. Clients may be expected to wear graduated compression bandages for up to 20-22 hours daily between sessions. This intensive phase of treatment typically continues until the affected extremities are decongested and volume is stabilized. Phase two of treatment focuses on long-term lymphedema self-management through daytime graduated compression garment use, night time use of short stretch compression bandaging, remedial exercises with graduated compression bandages or garments, daily skin care, and manual lymphatic drainage as required. Further information about treatment, management, and on-line resource links are available at Canadian Lymphedema & Rehabilitation Services, Inc. (www.canadianlymphedema.com).

There are a variety of training programs available for occupational therapists' consideration. The National Lymphedema Network offers a list of training programs that meet the established training standards to apply to sit the Lymphology Association of North America (LANA) certification exam. LANA requires the clinician to complete a minimum of 135 hours of academic training consisting of one third theoretical instruction and two thirds practical lab work, a minimum of one year of lymphedema clinical experience using CDT, followed by successful completion of the LANA exam.

Conclusion

In summary, as lymphedema is a chronic condition, all clients have to be expected to integrate self-management strategies into daily living activities. As clients with lymphedema also often report occupational performance complaints, occupational therapists have a crucial role in providing assessment and treatment services to meet the needs of this under-served Canadian population. CDT is a key component of treatment interventions for clients with lymphedema, and a variety of training opportunities are available to enable occupational therapists to incorporate this protocol into their practice.

Acknowledgements

The author would like to thank Jane Yi, Occupational Therapist, for her valuable feedback in the preparation of this manuscript.

References

- Cheville, A.L., McGarvey, C.L., Petrek, J.A., Russo, S.A., Taylor, M.E., & Thiadens, S.R.J. (2003). Lymphedema management. *Seminars in Radiation Oncology*, 13(3), 290-301.
- Crane, P. (2009). Management of sacroiliac dysfunction and lower extremity lymphedema using a comprehensive treatment approach: A case report. *Physiotherapy Theory and Practice*, 25(1), 37-43.
- Executive Committee of International Society of Lymphology (2009). The diagnosis and treatment of peripheral lymphedema. Consensus document of the International Society of Lymphology. *Lymphology*, 42(2), 51-60.
- Helms, G., Kuhn, T., Moser, L., Rimmel, E., & Kreienberg, R. (2009). Shoulder-arm morbidity in patients with sentinel node biopsy and complete axillary dissection – data from a prospective randomised trial. *European Journal of Surgical Oncology*, 35(7), 696-701.
- Ko, D.S.C., Lerner, R., Klose, G., & Cosimi, A.B. (1998). Effective treatment of lymphedema of the extremities. *Archives of Surgery*, 133(4), 452-458.
- Lymphology Association of North America. *Mission statement*. Retrieved from www.clt-lana.org
- Mayrovitz, H. N. (2009). The standard of care for lymphedema: Current concepts and physiological considerations. *Lymphatic Research & Biology*, 7(2), 101-108.
- McWayne, J., & Heiney, S. (2005). Psychologic and social sequelae of secondary lymphedema. *Cancer*, 104(3), 457-466.
- Mortimer, P.S. (1995). Managing lymphoedema. *Clinical and Experimental Dermatology*, 20, 98-106.
- National Lymphedema Network. *For Professionals*. Retrieved from www.lymphnet.org
- Radina, M.E. & Armer, J. M. (2001). Post-breast cancer lymphedema and the family: A qualitative investigation of families coping with chronic illness. *Journal of Family Nursing*, 7(3), 281-299.
- Ramos, S.M., O'Donnell, L.S., & Knight, G. (1999). Edema volume, not timing, is the key to success in lymphedema treatment. *The American Journal of Surgery*, 178(4), 311-315.
- Ridner, S. (2009). The psycho-social impact of lymphedema. *Lymphatic Research & Biology*, 7(2), 109-112.
- Soran, A., D'Angelo, G., Begovic, M., Ardic, F., Harlak, A., Wieand, H., et al. (2006). Breast cancer-related lymphedema – What are the significant predictors and how they affect the severity of lymphedema? *The Breast Journal*, 12(6), 536-543.
- Vignes, S., Porcher, R., Arrault, M., & Dupuy, A. (2007). Long-term management of breast cancer-related lymphedema after intensive decongestive physiotherapy. *Breast Cancer Research and Treatment*, 101(3), 285-290.
- Williams, A.F., Franks, P.J., & Moffatt, C.J. (2005). Lymphoedema: Estimating the size of the problem. *Palliative Medicine*, 19(4), 300-313.
- Woods, M., Tobin, M., & Mortimer, P. (1995). The psychosocial morbidity of breast cancer patients with lymphoedema. *Cancer Nursing*, 18(6), 467-471.

About the authors

Byron Shier, MBA, B.Sc. OT Reg. (B.C.), CLT, CHE, is Director of Canadian Lymphedema & Rehabilitation Services: www.canadianlymphedema.com. Byron has been a certified lymphedema therapist with Lymphology Association of North America (LANA) since 2002. He is a past guest lecturer at the University of Alberta, Department of Occupational Therapy. You may contact him at: lymphrehab@hotmail.com.