

AN AMERICAN HISTORY OF LYMPHOEDEMA MANAGEMENT

John MacDonald

'Never doubt that a small, group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.' These words of Margaret Mead, American anthropologist, are relevant to the history and current state of lymphoedema therapy in the USA. Just as with the history of infantile paralysis, cystic fibrosis and muscular dystrophy, progress in public awareness and professional involvement for lymphoedema has been the result of the efforts of a select few. As with these previous examples, the select few have developed a cooperative advocacy of both professionals and lay people.

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Lymphoedema awareness comes to America

Robert Lerner, MD, a general surgeon in New York City, deserves recognition as the father of lymphoedema awareness in the US. In the late 1980s, he visited the Foeldi clinic — a 145-bed hospital in Hinterzarten, Germany founded by Michael and Ethel Foeldi and devoted exclusively to the study and treatment of lymphoedema. He then founded the first, Vodder-influenced, Foeldi-method, lymphoedema treatment centre in the

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USA. Shortly after, he was joined by Guenter Klose, a certified manual lymph drainage/complete decongestive therapy (MLD/CDT) instructor, and a graduate of the Foeldi programme. In 1998, they wrote the first article to appear in an American medical journal describing CDT as a treatment of extremity lymphoedema (Ko et al, 1998). In the early 1990s, three Lerner clinics and affiliated training programmes were established in the east of the USA.

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As lymphoedema awareness began in New York, another pioneer was working independently in San Francisco. In 1987, Saskia Thiadens, a nurse, became interested in 'the swollen limb syndrome'. She opened the Aurora Lymphoedema Clinic. In recalling those days, Ms Thiadens said: 'At that time, not a single person in the United States could give me basic answers for understanding the swollen limb or how to treat it. Nor were physicians very supportive of my efforts. It was clear that lymphoedema and its treatment received little if any attention from the medical community nationwide. That's when I became aware of my mission.'

In 1988, Ms Thiadens founded the National Lymphoedema Network (NLN) (www.lymphnet.org). It was designed as an information resource for patients and medical professionals and served as a successful resource for public awareness and medical education. Perhaps the most important vision provided by Ms Thiadens was her decision to involve lymphoedema patients and their families in what might have been an exclusive professional organisation. Because of her insight, the NLN is now recognised as one of the most influential, multidisciplinary, lymphoedema organisations in the world.

The mustard seed takes root

Following the example given by Dr Lerner and Ms Thiadens, lymphoedema therapy certification courses began to be sponsored throughout much of the nation by private groups directed by Dr Lerner, Guenter Klose, Steve Noton and Josep Zuther. These courses, averaging 135 hours, are conducted by multiple groups with certified instructors. There are eight recognised US training schools now teaching the Vodder, Foeldi or Casley-Smith methods. Applicants must be physiotherapists, occupational therapists, therapist assistants or physicians. Originally, there were no specific required professional qualifications. Massage therapists and registered nurses could become certified, but recent Medicare and Medicaid reimbursement guideline changes have excluded these two groups. This is now a matter of heated debate.

Now there are about 3,500 certified lymphoedema therapists in the US. Most

work as independent contractors and are not affiliated with specific centres. The registered lymphoedema centres may be hospital based or free standing. The presence of an on-site physician medical director who is experienced in lymphoedema is a distinct rarity. It is difficult to estimate the number of lymphoedema centres in America as a central directory is not available. Some states, particularly in the south and north-west, have a critical scarcity of qualified lymphoedema support. There are only two inpatient lymphoedema programmes in the country.

While the number of trained therapists has increased dramatically, the acceptance and availability of lymphoedema programmes has been difficult and slow at best. However, the success that has been achieved over the past 26 years has been due, primarily, to the dedication of nurses, physiotherapists, massage therapists and concerned lay citizens, the vast majority being women.

Certification and academics

In 1999, the Lymphology Association of North America (LANA) was founded under the leadership of Joseph Feldman MD, Northwestern University. Its mission is to promote standards for management and to establish and maintain certification for professionals administering CDT. The requirements for LANA certification eligibility include: 135 hours of CDT training; one year's experience after training; 192 hours of college-level human anatomy, physiology and/or pathology. Certification will identify lymphoedema treatment as a specialty that requires advanced training and provides a basis from which insurance companies can establish more consistent reimbursement guidelines for Medicare and other US health insurance providers. To date, 750 therapists have been certified by LANA.

Physician involvement in patient care, research and academics has been a major

challenge. Notable medical academics such as Stanley Rockson at Stanford University and Marlys Witte and her late husband, Charles, at the University of Arizona, have made significant contributions. Physicians are becoming involved, but at a painfully slow pace. Lymphoedema is a neglected subject in American medical schools. Physicians showing interest represent dermatology, vascular surgery, physical medicine and family practice. Few medical schools have a lymphology teaching curriculum and the information medical trainees receive is from the occasional departmental lecture.

Reimbursement

In 1996, scattered medical acceptance for CDT, combined with nascent public involvement, created the need for reimbursement guidelines. It was obvious that the German experience could not be offered as our gold standard, as CDT treatments twice a day for 30 days were unlikely to be covered. In 1997, Florida became one of the first states to approve insurance cover for 10 CDT treatments. Lymphoedema therapy was placed under existing physiotherapy Medicare codes. Extension of therapy for more treatment sessions can be approved with validation by a physiotherapist. This deviation from the recognised global experience aroused significant criticism. Subsequent reports have demonstrated that in cases of lymphoedema Grades I and II, the results are comparable to those experienced in Germany. The Florida Protocol has served as a template model for government and private insurance for most of the USA.

Taking stock

The significant accomplishments for lymphoedema in America have included:

- ▶▶ The success of lay activist groups seeking recognition and funding for lymphoedema and lipoedema
- ▶▶ The LANA certification programme
- ▶▶ Recognition by the National Institute of Health (NIH) that lymphoedema is

a significant medical disease requiring funding for lymphology research

- ▶▶ The use of the internet for the continued support of patients
- ▶▶ Steady growth in the number of certified lymphoedema therapists
- ▶▶ Increased awareness of the symbiotic relationship between wound healing and lymphology.

There are still significant challenges for lymphoedema in America, including:

- ▶▶ Physician awareness and acceptance of basic lymphology and therapeutic options at both graduate and undergraduate level
- ▶▶ Reasonable government and private insurance reimbursement for treatment and maintenance garments
- ▶▶ Educating the medical community to the challenges of the underestimated prevalence of lipoedema
- ▶▶ Improved diagnostic tools for the diagnosis of lymphoedema and the quantification of specific therapies
- ▶▶ Finding a solid evidence base for the role of pneumatic pumping in the treatment of lymphoedema
- ▶▶ Expansion of refined basic lymphology research and properly executed clinical trials.

Summary

As with any new medical discipline, lymphoedema therapy has had growing pains. In America, the expansion of professional knowledge and availability of treatment has been significant. The challenge for the next decade is to refine this success. This progress must be accompanied by an increase in the academic pursuit of improved diagnostics, evidenced-based recommendations for therapy and basic scientific understanding of the role of the lymphatic system in wound healing. Much work remains to be done if we are to conquer the 'hidden epidemic'. **JL**

Ko DS, Lerner R, Klose G, Cosimi AB (1998) Effective treatment of lymphedema of the extremities. *Arch Surg* 133: 452–8