# USA-SOUTH AFRICAN PARTNERSHIP FOR LYMPHOEDEMA EDUCATION

Nicole L Stout, Jane Armer, Steve Norton, Vickie Parker, Cheryl Nikodem

Curricula for providing lymphoedema education varies internationally. The Lymphology Association of North America (LANA) has established curriculum criteria (135 hours), accepted as the standard model across the United States (US). This educational mode was successfully introduced in the Western Cape, South Africa (SA) in an inaugural course in 2008. This report outlines the necessary resources and preparation, the cultural experiences and challenges, and the mechanisms for training and ongoing support central to the success of this programme.

Kev words

Lymphoedema education Collaboration Traditional healer Cross-cultural education

ymphoedema is a chronic and debilitating condition. The nature of the disease is progressive unless treated with specialised techniques. The current standard of care for the treatment of lymphoedema, as outlined by the International Society of Lymphology (ISL), is complete decongestive therapy (CDT) (ISL, 2003). CDT is a multi-modal intervention employed by healthcare professionals with advanced education in treatment techniques. World-wide, CDT is the accepted standard of care (ISL, 2003); however, lymphoedema educational programmes for healthcare professionals

Nicole L Stout is Physical Therapist and Lymphedema Specialist, National Naval Medical Center, Breast Care Center, Bethesda, MD, USA; Jane M Armer is Professor, University of Missouri, Sinclair School of Nursing, Ellis Fischel Cancer Center, Columbia, MO, USA; Steve Norton is Executive Director and Norton School of Lymphatic Therapy Founder, Norton School of Lymphatic Therapy, Matawan, New Jersey, USA; Vickie Parker is Certified Lymphedema Therapist, Ellis Fischel Cancer Center, University of Missouri, USA; Cheryl Nikodem is Professor and Head Stellenbosch University Nursing Division and Professor at the School of Public Health, University of the Western Cape, South Africa

differ among countries. One common problem, almost ubiquitous worldwide, is the general lack of healthcare professionals with advanced lymphoedema education (Logan et al, 1996). This dearth is magnified in developing and emerging countries.

Cross-cultural educational programmes are challenging to implement and successfully sustain. International differences exist due to cultural and societal variations in healthcare needs and availability of

Educational programmes that are successful in one culture may not meet the specific needs of another, or may be difficult to extrapolate to other cultures in an economically feasible way.

care. Educational programmes that are successful in one culture may not meet the specific needs of another, or may be difficult to extrapolate to other cultures in an economically feasible way. The purpose of this report is to highlight the successful implementation of a United States (US) based lymphoedema educational curriculum to the healthcare market of South Africa. Planning, implementation, and sustainability challenges and successes will be highlighted.

# **Background**

The current curriculum for lymphoedema educational programmes has grown out of a European model, initiated and championed by the Dr Vodder School in Austria and the Földi Clinic in Germany (Földi et al, 1989; Kasseroller, 1998). In the early 1990s, Robert Lerner started the first CDT treatment and education centre in the United States, modelled after the Földi clinic (Lerner, 1998). The Lerner educational programme included didactic and practical education for healthcare professionals in an effort to improve the standard of care.

In 1998, the American Cancer Society (ACS) recognised a need for the lymphoedema community to convene an expert consensus workshop to define the current climate of lymphoedema treatment in the US (ACS, 1998). These workshops found that educational curricula in the US for healthcare professionals was grossly lacking in lymphoedema management (Thiadens, 1998). Therapists (including physical and occupational) were not receiving a basic level of knowledge in lymphoedema management that was adequate to treat this complex condition (Augustine et al, 1998; Walley et al, 1998). One recommendation from the ACS workshop was to create a national organisation to assess the current state of lymphoedema education and create criteria and guidelines for lymphoedema educational programmes. The outcome

was the formation of the Lymphology Association of North America (LANA).

Since its inception in 1999, LANA has set forth curriculum criteria for lymphoedema educational programmes. The criteria require 135 hours of formal classroom training for licensed medical practitioners through a format that is two-thirds practical laboratory teaching and one-third didactic learning. Students are tested throughout the curriculum to demonstrate competency and safety. After completing this course work and practice in a clinical setting for one year, students may sit for a voluntary national LANA specialty examination. The examination demonstrates a basic level of competency in managing lymphoedema.

The paradigm for continuing medical education (CME) in the US lends itself to the success of a twoweek training model. Medical providers are professionally licensed by their respective states and continuing education credits may be required to demonstrate continued competency and maintain their licences. In the US, employers (hospitals, medical clinics, ambulatory clinics, hospice centres, home health centres, etc) frequently support their healthcare professionals to obtain CME credits in the interest of maintaining their workforce. This may include paid salary and benefits while the practitioner is taking a CME class and often employer-paid travel. The time-intensive, two-week curriculum may be a barrier to implementing such a course in other cultures where healthcare resources may be more limited. Although the authors were successful in recruiting therapists and their employers to embrace this model in South Africa, this may not be true of all countries. Efforts should be made to confirm the willingness of interested stakeholders to subscribe to such a CME format.

#### **Methods**

Building upon more than two decades of collaboration between the University of Missouri and the University of Western Cape (UWC), and leveraging the trust built up between these two institutions, an initial proposal was developed in 2006 and funded in 2007 to explore research and educational partnerships in breast cancer-related lymphoedema. One outcome was an increased awareness of the gaps in formal education in lymphoedema assessment and management in South Africa and the African continent in general. Lymphoedema is a major source of disability in Africa, leading to significant health and workforce deficiencies.

Based on the success of the first exchange programme, a second collaboration was developed in 2008 to continue the exchange of expertise, skill-training and education for lymphoedema best practice. This collaboration also tried to evaluate the current state of lymphoedema management and to integrate specialised lymphoedema therapy with traditional, indigenous and homeopathic approaches for disease management. These aims culminated in the inaugural lymphoedema training class in Western Cape.

Through a shared vision and commitment, a partnership with a well-recognised US lymphoedema education programme was developed to provide an established curriculum and optimal

clinical and educational expertise to the students. Lymphoedema instructors donated their time and curricular materials were shared through a collaborative agreement. The academic partners at UWC allocated space for the programme and arranged for the course to occur over the university's winter break to minimise disruption and to assure adequate availability of resources at the university, such as room space, laboratory room space, plinths/cots, use of audiovisual equipment. A tuition fee was set by UWC for the two-week class. Students were required to be licensed healthcare professionals (physical, occupational, or massage therapists, nurses or physicians).

#### **Results**

In 2008, the first lymphoedema education class in South Africa took place in Cape Town at UWC. Twenty-two therapists were certified according to the 135-hour curriculum standard. The programme followed the LANA criteria of dedicating two-thirds of the curriculum to practical learning and one-third to didactic teaching. Competency testing was conducted using pre- and post-class written examinations, practical laboratory skills testing and case study presentations (Figure 1).



Figure 1: Practical instruction in the laboratory.

In 2009 a second class will be undertaken in Pretoria, South Africa. This will provide education for additional therapists as well as enabling the inception of an instructor training component for future programme viability and longterm sustainability.

# **Challenges and barriers**

This programme was successfully implemented by overcoming a number of challenges and barriers including geographical, cultural, and logistical obstacles. The authors also worked to accommodate the current healthcare environment in South Africa by considering practitioner standards, indigenous healthcare norms, and cost considerations. Some barriers were anticipated and addressed ahead of time. However, there were many unanticipated challenges that arose on-site and required the creativity, innovative problem-solving and flexibility of the team.

#### Geographical

Considering the rigour of the teaching schedule, the health of the instructor is vital to ensure a seamless course structure. Also, financial resources may not be available to allow for a back-up instructor should the primary instructor fall ill. Thus, geographically, the challenge of acclimatising to the time zone and seasonal differences should be taken into account. Fatigue, dehydration, and nutrition should all be considered. Potentially malicious gastrointestinal irritants, including indigenous water and unfamiliar foods should be avoided in an effort to maintain good health.

#### Cultural

It is imperative to identify and to accommodate cultural differences before the class begins. The indigenous students, patients, and local assisting faculty may be accustomed to norms different from those of Western culture. Language barriers should be considered, including local dialects and slang. Although the course may be designated to be delivered in English, the authors' experience is that understanding the spoken English

word and comprehending the meaning may not be easily interchangeable for students and patients for whom English is not their first language (Schlemmer and Mash, 2006). This necessitates a slower delivery pace for the curriculum and frequent review in written and verbal forms.

Approaches to socialising in an educational setting vary among cultures. Didactic lecture should be delivered in a timeframe tailored to accommodate breaks and lunches in accordance with cultural customs. Also efforts should be made to accommodate societal norms with regard to clinical laboratory teaching. If students are to work in small groups, cultural issues relating to gender and ethnicity should be taken into account. Are students comfortable disrobing with a multi-gender class? Are students comfortable practicing manual skills on one another if they are from different ethnic or racial backgrounds? Are there language barriers that may preclude some students from working together? Are there cultural or religious practices which impact the length of the day or days of the week that a class can take place? Each of these questions must be asked and not assumed based on our experiences in Western culture.

## Logistical

The authors' team successfully identified and problem-solved many resource and logistical challenges ahead of time. The layout of classroom space was organised in advance as well as the technical audiovisual needs. One major challenge was procuring adequate supplies for the students to use in the classroom. CDT requires that students spend a considerable amount of time learning compression bandaging techniques. The unique nature of compression bandaging for lymphoedema requires specialised materials and supplies that were not readily available in South Africa. Preemptive planning enabled the authors to locate a vendor on the continent and ensure that there were sufficient on-site supplies for the course.

However, shipping materials overseas was not without challenges. Educational books, necessary for the class and shipped well in advance, were held by customs officials in South Africa and negotiations were required to have them released in a timely and cost-effective manner. Unfortunately, this was not achieved until after the class was completed.

#### Healthcare environment

The healthcare environment of South Africa was foremost in the authors' considerations when planning this educational programme. The team identified the standard practitioners who would be treating lymphoedema in the South African healthcare model. Information about the knowledge and background education of the class participants regarding lymphoedema management was obtained to help structure the classwork to meet student needs. Further, the climate of lymphoedema awareness among the general population and among healthcare professionals was considered to help target educational needs outside of the lymphoedema therapy class. For example, upon learning that lymphoedema recognition among South African medical practitioners was poor, a partnership with the Cancer Association of South Africa (CANSA) was developed to enable a representative from their organisation to take the class. This effort was fruitful as we successfully worked with CANSA while on-site to develop a clinical educational video describing standard CDT treatment for patients. This is now used and distributed by CANSA to promote education to families and healthcare professionals across the country.



Figure 2: Traditional healer addressing the class.

A cultural norm specific to South African health care and medical practice is the acceptance and widespread use of traditional healers. The vocation of a traditional healer is passed down through generations. Healers undertake considerable training to learn about specific natural remedies. South African culture embraces traditional healers as a part of the medical system and their presence is woven into the fabric of the medical culture. The authors successfully melded the role of the traditional healer into the class framework. A traditional healer and interpreter were invited to come to class to be interviewed in the presence of students to learn about ways that healers may be managing patients with swelling and other cancer treatment side-effects (Figure 2).

In any healthcare environment, the element of trust is paramount to the patient/healthcare professional relationship. In the South African healthcare system, many different barriers exist to improving this relationship. First, is the issue of trusting the healthcare community. Many South African people, by virtue of their indigenous cultural beliefs, rely heavily on traditional forms of medicine rather than modern medical interventions. This posed a particularly interesting challenge in trying to bring patients into the class for demonstration. The racial and economic disparities are also great across this society and posed a further challenge to relationship building.

In earlier partnerships (2006/7) between the University of Missouri and the UWC, community liaisons were developed within the formal and informal healthcare delivery systems, and among elders in the community in the Western Cape region. As a result, a community outreach worker, previously known to the team, was recruited to assist in identification of cancer survivors with lymphoedema. The survivors were invited to participate in an ethics committee-approved survey about the experience of living with and managing lymphoedema. The relationship with the community, facilitated by the academic partnership

between the American and South African researchers, helped to build up the mutual trust that was essential for the success of the programme. It is hoped that this will have long-term implications for continued community acceptance of the lymphoedema clinics that will form as a result of the class.

Earlier experiences also led to the recruitment of the patients for the lymphoedema class, who came to share their condition and receive a treatment demonstration to foster a clinical learning experience for the students (Figure 3; Box 1).

Many South African people, by virtue of their indigenous cultural beliefs, rely heavily on traditional forms of medicine rather than modern medical interventions. This posed a particularly interesting challenge in trying to bring patients into the class for demonstration.

Healthcare costs and reimbursement structures were also factors in establishing and carrying out this educational programme. Mechanisms to promote fiscal sustainability were identified, including finding ample supplies through local vendors and identifying current payment structures within the South African healthcare model that could encompass lymphoedema treatment. Discussions were started with a major third-party payer in the South African health system regarding payment for services. This meeting highlighted the mechanisms needed to expand payment for lymphoedema services and the avenues that local therapists may use to work towards more comprehensive coverage for services. This relationship is ongoing as we work toward sharing awareness about lymphoedema occurrence and best practice guidelines with the national organisation of South African health insurers.

The class tuition cost was set at a modest level so as to be commensurate with the prevailing economic trends. Currency exchange rates should always be considered along with a threshold for economic feasibility, as this will be quite variable from one country to another. Budgeting should cover all expenses related to the class, including the instructor's travel and accommodation expenses, as well as potential unforeseen costs, such as, on this occasion, retrieving items from customs officials.

# Sustainability

The greatest challenge in providing international educational programmes is how to build a network of local resources and support for the programme to eventually function independently. An educational initiative such as this will not be sustained without ongoing local and regional support from indigenous practitioners, payers and other stakeholders (Mathews et al, 2007).

To promote such independence, a number of ongoing programmes were established for collaboration and advocacy in South Africa as an optimal model of integrating services (Candeira et al, 1998).

First, the community liaison programme was established as an ongoing project to promote communication and education between patients and healthcare providers. The liaison serves as the conduit for educational information and support to build the bridge of trust between the patient and healthcare professional when they may have disparate beliefs about the best medical approach.

Second, an educational programme was established with CANSA for lymphoedema recognition and education. CANSA worked with our team of instructors to develop an educational video that is now widely distributed and used to promote lymphoedema awareness and to educate patients, healthcare professionals and insurers about lymphoedema and its treatment.

# Box I

# Clinical experience: hands on in the classroom

A part of the lymphoedema educational curriculum encourages patient demonstration in the classroom. This helps to give the students a realistic clinical perspective on what they will see in the course of their practice. One patient who chose to attend our class and volunteer for treatment did so with great scepticism for this new intervention. She related to the class a 10-year history of managing her own wound and swelling care using a natural remedy recommended to her by a traditional healer. Although she had substantial swelling and an impressive wound (Figures 3a and 3b), she was not amenable to foregoing her current remedy in favour of a new treatment.

The instructor's goal was to demonstrate to the class and to the patient that CDT techniques would be effective in helping her to manage her condition, but that they did not have to replace the remedies that she was already using. CDT can often be used in conjunction with wound care topical ointments and dressings. In this situation, the patient was using a mixture of tar, glycerin and honey as a topical agent. With the expert guidance of the instructor, the patient was educated about what interventions could be helpful to incorporate, how different modalities such as compression bandages could be applied, and what the benefits may be. Upon realisation that her treatment regimen would not be usurped, she trusted us to apply compression bandages to her leg (Figure 3c).

When the patient returned to the class the following day, before removing the bandages she commented to the class that she felt this technique, 'was not good for people with wounds, as it did not allow the legs to breathe'. She also stated that she would not continue with the bandaging.

However, upon removal of the compression bandages, she was stunned by the overnight change to her limb swelling and agreed that



Figure 3a: Patient demonstration in class. Condition of legs before the application of compression therapy to the wound.



Figure 3b: Venous wound on the patient's leg.



Figure 3c: Application of compression bandages in class. Bandages were used in conjunction with the patient's current regimen for wound care.

perhaps this was a treatment worth continuing. Trust was built with this woman by demonstrating that a newly-recommended treatment could be used hand-in-hand with her usual care. She felt valued in the discussions about how to proceed with her care and did not feel as though her beliefs

about her current medical intervention were being discounted by the healthcare professionals.

Upon completion of the class, the patient was happy to continue follow-up for her treatment with one of our newly certified lymphoedema specialists.

Third, an open dialogue is still ongoing with third-party payers offering proposals for payer education and novel payment models. These programmes will continue to sustain a culture of lymphoedema treatment that is commensurate with international standards.

In order to offer ongoing support for the newly-certified therapists, several mechanisms for continued student-to-student and student-toinstructor communication were set up. First, an e-mail list was established to include all class participants and instructors. This seemingly simple solution has enabled regular communication when questions arise. Further, because responses are delivered to each registrant, all who participate can learn from the others' questions and interactions with expert instructors. Second, the therapist group has also established a network in South Africa. The group is meeting regionally in an effort to present case studies and literature review discussions to facilitate ongoing education and mentored learning.

### **Conclusion**

Education for healthcare professionals in the specialised techniques required to treat lymphoedema is disparate world-wide. The authors' experience in South Africa presents an optimal construct for planning, implementing and sustaining a lymphoedema education programme across international boundaries. Extrapolation of the US model requires a proactive team approach that includes academic, clinical and community support. Precourse planning should begin well



Figure 4: The inaugural 2008 UWC lymphoedema class.

in advance of undertaking such an initiative to ensure that appropriate resources are in place, not only to carry out the class, but to enable an ongoing, sustainable programme. In the authors' opinion, educators, students and patients involved in this collaborative effort were provided with a life-changing experience through this educational offering and unique cultural experience (Figure 4).

# Acknowledgement

This project was funded in part by the University of Missouri–South Africa Exchange Program (UM-SAEP).

#### References

American Cancer Society (1998) American Cancer Society workshop on breast cancer treatment-related lymphedema. New York, USA. February 20–22, 1997. *Cancer* 83(12 Suppl American): 2775–890

Augustine E, Corn M, Danoff J (1998) Lymphedema management training for physical therapy students in the United States. *Cancer* 83(12 Suppl American): 2869–73

Candeira M, Schuch W, Greiner L, Buckley L, Gold H, Langer A, et al (1998) American Cancer Society Lymphedema Workshop: workgroup v collaboration and advocacy. *Cancer* 83(12 Suppl American): 2888–90

Földi E, Földi M, Clodius L (1989) The lymphedema chaos: a lancet. *Ann Plast Surg* **22**(6): 505–15

International Society of Lymphology (2003) The diagnosis and treatment of peripheral lymphedema. Consensus document of the International Society of Lymphology. *Lymphology* **36(2)**: 84–91

Kasseroller RG (1998) The Vodder School: the Vodder method. *Cancer* **83(12 Suppl American)**: 2840–2

Lerner R (1998) Complete decongestive physiotherapy and the Lerner Lymphedema Services Academy of Lymphatic Studies (the Lerner School). *Cancer* **83(12 Suppl American)**: 2861–3

Logan V, Barclay S, Caan W, McCabe J, Reid M (1996) Knowledge of lymphoedema among primary health care teams: a questionnaire survey. *Br J Gen Pract* 46(411): 607–8

Mathews M, Bursey G, Park A, Hodgson P, West P, Church J (2007) Increasing public and provider knowledge of lymphedema: evaluation of the lymphedema roadshow. *J Cancer Educ* **22**(2): 105–7

Schlemmer A, Mash B (2006) The effects of a language barrier in a South African district hospital. S Afr Med J 96(10): 1084–7

Thiadens SR (1998) Current status of education and treatment resources for lymphedema. *Cancer* **83(12 Suppl American)**: 2864–8

Walley DR, Augustine E, Saslow D, Bailey S, Jeffs E, Lasinski B, et al (1998) American Cancer Society Lymphedema Workshop. Workgroup IV: Lymphedema treatment resources — professional education and availability of patient services. *Cancer* 83(12 Suppl American): 2886–7

# **Key points**

- The current standard of care for the conservative treatment of lymphoedema, as outlined by the International Society of Lymphology (ISL), is complete decongestive therapy (CDT), a multi-modal intervention employed by healthcare professionals with advanced education in treatment techniques.
- A worldwide deficit of healthcare professionals with advanced lymphoedema education exists.
- Substantial planning and preparation are necessary to successfully implement and sustain cross-cultural educational programmes.
- ➤ A cross-cultural collaboration of stakeholders with common interests and goals is optimal to promote educational partnerships.
- In a cross-cultural education model, it is imperative to merge curricular approaches with elements of the indigenous culture and medical paradigms.