

The Evolution of Lymphedema Care in the United States

I have been involved in lymphedema care for the past thirty years, having received my training in Germany, where Complete Decongestive Therapy (CDT) for the treatment and management of lymphedema has been well established since the 1970s. After moving to the U.S. in the early 1990s I learned that in this country adequate lymphedema care was not a well known part of the medical field; there were a handful of treatment centers scattered throughout the country, and institutions for the training and education of health care practitioners in lymphedema management were non-existent. Back in those days I was also talking to a large number of physicians about lymphedema and was surprised to learn that the vast majority of these doctors, even specialists such as vascular surgeons and oncologists, did not know what lymphedema was, or how it should be treated. I was even told that lymphedema was a “non-issue” in the U.S. and a “European problem”. Patients with lymphedematous extremities were told that there is nothing that could be done and that they would have to live with their swollen arms or legs.

Thankfully this situation has improved over the past decades; many lymphedema treatment centers are now established throughout the country, and there are a number of excellent schools providing high quality training in lymphedema management to health care practitioners. CDT is now recognized in the United States as the gold standard treatment for lymphedema, and health care providers generally do a good job in providing information on this condition. With the development of the Internet we saw the evolution of a large number of websites dedicated to lymphedema and its care, providing patients affected by lymphedema with the information they need, which is of great importance especially for those patients who do not receive adequate information from their physicians.

Progress has also been made in alternative or additional treatment modalities for lymphedema, such as surgical procedures and new generation intermittent pneumatic compression (IPC).

Various surgical procedures for the treatment of lymphedema have been practiced for over a century and advancements in medical technologies have led to increased discussion of the role surgical treatment, such as lympho-lymphatic or lympho-venous anastomoses and vascularized lymph node transfers. Recent research indicates that the surgical approach to treat lymphedema has beneficial effects for a select group of patients; however, there is a broad consensus that surgical procedures do not eliminate the need of CDT pre as well as post-operatively, and should act as an adjunct to conservative treatment protocols. Any surgical approach to treat lymphedema should be reserved for those cases when conservative treatments have clearly been unsuccessful or when the achieved success of conservative measures can no longer be maintained. An important component to determine whether any surgical procedure for lymphedema is indicated is to weigh the potential benefit of the specific surgical procedure against the risks associated with it. Other considerations should include the individual needs and goals of the patient, and the medical expertise of the surgical team.

Recent studies suggest that there is a potential place for newer generation IPC's as a beneficial adjunct treatment to control lymphedema, specifically for individuals affected by chronic lymphedema with limited or no access to medical care, or in those cases when physical limitations of the individual may

result in challenges controlling the lymphedema independently in the self-administered maintenance phase directly following CDT treatments. IPC's labeled as Type III pumps are advanced segmented devices with calibrated gradient pressure with a manual control on at least three outflow ports of the device that can deliver an individually determined pressure to each compartment of the unit. With these newer generation devices manual adjustments in the pressure in the individual compartments and/or the length and frequencies of the compression cycles can be made, which is not possible with older, non-segmented IPC's without gradient pressure.

It is important to point out that IPC's should not be used as a stand-alone therapy for lymphedema, and that compression therapy with bandages and/or garments must be continued following the use of IPC's to prevent a rebound of swelling. Optimal treatment and management of lymphedema always necessitates a treatment approach that is tailored to the patient's specific needs. IPC devices can be an additional tool in a multi-modality approach to effectively treat lymphedema; however, no pneumatic compression device is able to replace complete decongestive therapy.

So the question if lymphedema management in the U.S. has evolved can certainly be answered with a "yes". However, continued improvement is certainly needed in areas such as the education of physicians and other health care providers in the effective treatment of lymphedema (the lymphatic system is hardly covered in medical school), health care coverage for compression garments and research on the impact of early and late onset lymphedema on the psycho-social and functional health of affected patients.

Many outstanding researchers, educators and individuals involved in the field are constantly working to further improve lymphedema care in this country – the future looks bright!