

Lymphedema and its Impact on Quality of Life

Chronic lymphedema is considered to be a progressive condition, regardless of its classification of either primary or secondary, and cannot simply be described as an accumulation of protein-rich fluid. It is a chronic, degenerative and inflammatory process affecting the soft tissues, skin, lymph vessels and nodes of the extremities, trunk, abdomen, head and neck, and exterior genitalia. Lymphedema can develop anytime during the course of a lifetime in primary cases, in secondary cases it may occur immediately following the surgical procedure or trauma, within a few months, a couple of years, or twenty years or more after treatment, and may result in severe and often disabling swelling.

That chronic lymphedema also considerably impacts the health-related quality of life (QoL) and psychological well-being of patients around the globe affected by this disease is known and confirmed by research for quite some time^{1,2,3}. The highest incidence of secondary lymphedema in the United States is observed following surgery and radiation for malignancies, particularly among those individuals affected by breast cancer, which is conceivably the reason why the majority of research on the impact of lymphedema on QoL was conducted on survivors of breast cancer with subsequent lymphedema (breast cancer related lymphedema/BCRL). The results of this research clearly indicate that health-related QoL was significantly lower in breast cancer survivors with diagnosed lymphedema or with arm symptoms without diagnosed lymphedema, compared with survivors without lymphedema or arm symptoms⁴. Any woman treated for breast cancer has a risk of developing lymphedema during or after the surgical/radiation/chemotherapy treatment necessary to eradicate the tumor. The impact of these procedures on the sufficiency of the lymphatic system may result in the onset of more or less lymphatic swelling in almost one woman in two. However, the literature also shows that the QoL of individuals affected by primary lymphedema and other forms of secondary lymphedema is negatively affected as well by this chronic condition. In fact, several studies indicate that patients affected by chronic edema of the lower extremities reported a higher impact on QoL than individuals with upper extremity lymphedema^{5,6,7}. It is also important to point out that the negative effects on QoL of lymphedema in many cases extends to the families of those living and coping with chronic edema^{8,9}.

As soon as, and sometimes before the swelling manifests itself, patients are confronted by esthetic problems (skin changes, increase in extremity size, ill-fitting clothing), functional problems (pain, stiffness, numbness, functional limitations, limitations in range of motion in the affected extremity, compromised normal activities of daily living and occupational responsibilities), and psychological problems (negative self-identity, emotional disturbance, stress, negative impact on family life, social isolation, perceived reduced sexuality). When some patients realize that lymphedema is a chronic disease requiring life-long management, these problems may intensify, and patients feel that coping with the swelling is more demanding than the treatment of the disease that caused lymphedema in the first place.

In order to effectively combat not only the swelling, but also the negative impact of lymphedema on psychological well-being, early diagnosis, evaluation and coordinated multi-disciplinary treatment strategies by certified lymphedema therapists and qualified health care professionals are imperative.

By definition, the goal of all treatment is to improve the patient's state of health; addressing the quality of life consequences of the patient has an important role to play alongside the objective of reducing limb volume.

Studies indicate that QoL improves with reduction in limb volume¹⁰; early diagnosis and subsequent efficient therapeutic intervention for lymphedema is therefore crucial to optimal treatment outcomes. However, effective lymphedema management should not only include comprehensive treatment measures by qualified health care providers to reduce the swelling, combined with education of the patients in regard to self-care measures; it should also address the QoL consequences of the disease and improve health-related QoL and psychological well-being by evaluating psychological and psychosocial criteria, and educating the patient on social support groups and interactive support.

Besides treating the lymphedema, the lymphedema therapist plays an important role in educating the patient in regard to the treatment measures and self-care techniques (self-MLD, self-bandaging, skin and nail care, etc). Oftentimes patients have a hard time accepting the need for the application of bulky padded compression bandages on the affected extremity during the intensive phase (phase 1) of Complete Decongestive Therapy; compression bandages are necessary to address the fluctuating volume of the lymphedema during this intensive phase, in which the patient is treated ideally on a daily basis. In order to reduce anxiety and improve patient compliance, it is crucial for the patient to know, that the need for compression bandages is only temporary. Once the swollen body part is decongested and the patient transitions into phase 2 of CDT (self-management phase), the bandages will be replaced by fitted compression garments.

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References:

1. Fu M, Ridner SH, Hu SH, Cormier JC, Armer JM. Psychosocial impact of lymphedema: a systematic review of literature (2004–2011). *Psycho-Oncology* 2013; 22(7):1466-1484
2. McWayne J, Heiney SP. Psychologic and social sequelae of secondary lymphedema: a review. *Cancer* 2005;104(3):457–466
3. Ridner SH et al. Breast cancer treatment related lymphedema self-care; education, practices symptoms, and quality of life. *Support Care Cancer*, 2011; 19(5):631-637

4. R.Ahmed et al. Lymphedema and Quality of Life in Breast Cancer Survivors: The Iowa Women's Health Study. *J Clin Oncol.* 2008 Dec 10; 26(35): 5689–5696. Published online 2008 Nov 10. doi: 10.1200/JCO.2008.16.4731
5. Greene A, Meskell P. The impact of lower limb chronic oedema on patients' quality of life. *Int Wound J* 2017; 14:561–568.
6. Moffatt CJ, Aubeeluck A, Franks PJ, Doherty D, Mortimer P, Quere I. Psychological factors in chronic oedema: A case-control study. *Lymphat Res Biol* 2017; 15:252–260.
7. Moffatt CJ, Doherty DC, Franks PJ, Mortimer PS. Community based treatment for chronic edema: An effective service model. *Lymphat Res Biol* 2018; 16:92–99.
8. Radina ME, Armer JM. Post-breast cancer lymphedema and the family: A qualitative investigation of families coping with chronic illness. *J Fam Nurs* 2001;7(3):281–299.
9. Radina ME, Armer JM. Surviving breast cancer and living with lymphedema: resiliency among women in the context of their families. *J Fam Nurs* 2004;10(4):485–505
10. Mirolo BR, Bunce IH, Chapman M, et al: Psychosocial benefits of postmastectomy lymphedema therapy. *Cancer Nurs* 18:197-205, 1995