

NLN

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The NLN Mission Statement

The mission of the NLN is to create awareness of lymphedema through education and to promote and support the availability of quality medical treatment for all individuals at risk for or affected by lymphedema.

The NLN is dedicated to:

- ◆ promoting research into the causes, prevention and treatment of lymphedema;
- ◆ securing adequate insurance coverage for medically necessary, safe and effective treatment;
- ◆ expanding the number and geographical distribution of lymphedema treatment facilities and certified therapists.

To achieve these goals, the NLN disseminates information about lymphedema to health care professionals so they can appropriately counsel their patients on its avoidance, and prescribe safe, effective treatment for those affected by this condition. The NLN also provides this information to the general public.

Symptoms and Co-Morbidities Associated With Breast Cancer Treatment-Related Lymphedema

By Sheila H. Ridner, PhD, MSN, MSHSA, RN, ACNP-C

Although the presence of lymphedema in breast cancer survivors was not documented formally in medical literature until the late 1890s, its occurrence most likely parallels the history of surgical removal of the breast and surrounding structures that was documented early in the second century by Galen, a Greek physician (Lewison, 1955). Written acknowledgement by physicians of the severity of the problems caused by breast cancer treatment-related lymphedema can be found in a 1908 publication of *The Lancet*, when surgeon W. S. Handley called "brawny swelling" of the arm one of the worst complications of breast cancer. At that time, arm amputation was the only treatment for the swelling. Handley, concerned about the swollen arm and possible limb amputation, developed a technique he hoped would relieve the condition. In this first primitive procedure, Handley attempted to recreate the lymphatic system by burying silk threads from the wrist to the chest wall. Immediate improvement in arm swelling was observed; however, this procedure proved to be ineffective

because of resulting infections and the body rejecting the threads (Brorson, 2000; Handley, 1908). Since Handley's time, various techniques have been tried to stop breast cancer treatment-related lymphedema. Most recently, in hopes of, if not eliminating breast cancer treatment-related lymphedema, at least reducing it, surgeons have begun to use sentinel node biopsies in lieu of full axillary lymphatic dissections to stage breast cancer. However, because breast cancer treatment-related lymphedema has many causes, this change alone has not reduced the risk of developing breast cancer treatment-related lymphedema to zero. Thus, almost 2000 years after the first recorded breast surgery, treatment-related lymphedema remains a problem for possibly 15% to 28% of breast cancer survivors.

Fortunately, during the almost 100 years that have elapsed since Handley's procedure, lymphedema treatment methods have advanced so that amputation is no longer the treatment of choice. Unfortunately, despite advancements in lymphedema treatment

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PATIENT SUMMIT

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August 10, 2005

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Symptoms...

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methods, breast cancer survivors who have lymphedema continue to say that their quality of life (QOL) is poorer than it was before they developed lymphedema. They also express frustration that few healthcare providers seem to understand the difficulties patients encounter because of lymphedema and that these same healthcare providers often avoid talking to them about lymphedema and the problems associated with it because they don't know what to do about it.

A review of current scientific literature reveals that there is, indeed, a difference in level of QOL experienced by breast cancer survivors with lymphedema when compared to QOL of breast cancer survivors without lymphedema.

Additionally, in a study completed in 2003 by Ridner, when measured by three different quality of life tools, breast cancer survivors with lymphedema scored significantly lower in QOL than did breast cancer survivors without lymphedema. This poorer QOL was present both in women who had undergone lymphedema treatment and were completing at-home self-care and in those women who had undergone lymphedema treatment, but had discontinued most recommended at-home self-care activities.

Why does this quality of life change happen to breast cancer survivors who develop lymphedema? Why does therapy for limb volume reduction and at-home self-care not appear to return these women to previously enjoyed levels of quality of life? Is this long-term change in QOL related to the chronic nature of lymphedema and/or the burdensome arm self-care activities that are necessary for the rest of their lives? Or do other factors contribute to this problem?

This article will provide research-based information about symptoms (patient reported problems that indicate a change from normal levels of functioning, sensation, or appearance) and possible co-morbid (co-existing) conditions that may continue to influence the QOL

experienced by breast cancer survivors with lymphedema after limb volume reduction treatment.

Symptoms

Treatment-related outcomes and symptoms other than limb size reduction have been evaluated in lymphedema studies in the past few years to evaluate effectiveness of various types of lymphedema therapy provided to breast cancer survivors from CDT to pumps. Typically, physical symptoms such as aches, pain, tightness, burning pain, cramps, discomfort, heaviness, general mobility, grip and muscle strength were evaluated. Psychological/emotional symptoms such as altered body image, feelings of abandonment by healthcare professionals, depression and psychological distress also have been assessed in some studies. In many studies, these symptoms improved either temporarily or not at all following various types of lymphedema treatments, and poorer general health and poorer adjustment to illness have been documented in breast cancer survivors with lymphedema (Andersen et al. 2000; Carter, 1997; Casley-Smith et al., 1993; Cluzan et al., 1996; Johansson et al., 1998; Mirolo et al., 1995; Piller & Thelander, 1998; Tobin et al., 1993; Velanovick & Szynaski, 1999; Woods, 1993). Because most of these studies did not compare symptoms in breast cancer survivors with and without lymphedema, it remained unclear as to whether or not these problems were related to lymphedema or to the breast cancer treatment itself.

In 2003, Ridner conducted a study that compared symptoms/problems and QOL experienced by breast cancer survivors with lymphedema to those experienced by breast cancer survivors without breast cancer-related lymphedema. A total of 128 breast cancer survivors took part in the study: 64 women with breast cancer treatment-related lymphedema and 64 women without breast cancer treatment-related lymphedema. Differences in QOL and symptoms/problems were clearly identified. QOL was significantly poorer in

those with lymphedema. Physical symptoms that were statistically significant ($p < .01$) in breast cancer survivors with treatment-related lymphedema included alteration in limb sensation (heaviness, tightness, aching, burning, swelling, hardness, stabbing, and pins and needles), decreased physical activity and fatigue. Emotional symptoms included loss of confidence in body and psychological distress. Additionally, when participants in this study were asked to write about problems they experienced because of their lymphedema, other problems emerged. Many commented that the swollen arm made it hard to sleep, "I can't sleep. It wakes me up at night." Others discussed self-imposed limitations such as giving up their favorite recreational activities. Several were fearful they would further injure their arms, "I am afraid to participate in softball for fear of injuring my arm." Problems with everyday activities such as wearing clothes and jewelry were also discussed, "Wedding rings are very tight," or, "Regular clothes sometimes do not fit over my arm."

These findings indicate that multiple stressful physical and psychological symptoms exist in breast cancer survivors with lymphedema and that treatment designed solely to reduce limb volume may insufficiently relieve these symptoms. It is not hard to understand why women who have odd sensations in their arms, fear further injury of the swollen arm, become less active and can no longer wear their previous clothes or jewelry, may experience a decline in QOL.

Co-Morbid Conditions

Obesity is thought to be both a risk factor for developing lymphedema after breast cancer treatment and a complicating factor in long-term management of the condition. In 1974, a group of scientists reviewed medical records of 1,551 breast cancer patients treated between 1940 and 1965 (Say & Donegan, 1974); they found individuals with a body weight over 200 pounds were more likely to have postoperative arm swelling than those

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Letters To The Editor

Dear Editor,

I had a mastectomy in 1996 and removal of the lymph glands. I have always been worried about what would happen if I was injured and unconscious. I run a small dairy in Israel producing a wide variety of cheeses and milk products for home (kibbutz) consumption. In November 2003, I had a huge accident where someone reversed a tractor into me, pinning me against the wall of my milk tank bay. After being saved from certain death by my quick-thinking husband and laid out on the porch with a comminuted open fracture gushing blood from my right arm, I and my husband were constantly explaining or arguing with paramedics and healthcare professionals that no procedures be done on my left (affected) arm.

Luckily, once it was brought to their attention, most of the medical personnel complied, but a few we had to really shout at (this is the wild Middle East). Now I am so relieved to have the bracelet! It is just not something that doctors, etc. think about here. Even if they do know, as most of the nurses did, it still has to be pointed out.

So there is another story for you all! I will now read the leaflets you sent. This is a wonderful initiative and will save lots of women a lot of worry about what might happen if they find themselves in a predicament.

Thank you all again!

Margaret Ingram and
Alon Melamed
Israel

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Symptoms...

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weighing less than 200 pounds. Although little research has been done since 1974 to specifically study the influence of obesity on breast cancer treatment-related lymphedema, and long-term studies following breast cancer patients' weight and arm volume changes have yet to be done, some studies have measured Body Mass Index (BMI) in breast cancer survivors with and without lymphedema. In one study, higher BMI was found in breast cancer survivors with lymphedema than in those without lymphedema, and obese individuals experienced severe lymphedema more frequently than non-obese women (Johansson et al., 2002).

In the study conducted by Ridner in 2003, co-morbid conditions also were assessed. Obesity emerged as the only major co-morbid condition. Breast cancer survivors with lymphedema, on average, were obese by World Health Organization standards with a BMI of 30.23. Those breast cancer survivors without lymphedema were overweight with a BMI averaging 26.70. Additionally individuals with a BMI over 30 had more total symptoms, more severe symptoms and larger extra-cellular arm fluid volume differences when compared to their unaffected arm.

Cellulitis or infection in the affected limb is also a co-morbid condition in some breast cancer survivors with lymphedema. Individuals often report waking up at home in the morning with red, hot arms that had not been symptomatic when they went to bed. Infections such as this can be a one-time event, or become a series of annoying reoccurring infections that require IV antibiotics for treatment.

Pain can also accompany lymphedema. Some patients report sharp and stabbing pain in their arms that is not related to a known infection. Others frequently experience sensations in the arm such as tightness, burning, and pins and needles.

Clearly, lymphedema occurring after breast cancer involves more than just a

swollen arm. It is a disruptive condition accompanied by complex physical and psychological symptoms and some patients experience co-morbid conditions. What are the implications of these symptoms and co-morbidities for breast cancer survivors and their healthcare providers? In term of symptoms, it is important for lymphedema therapists and other healthcare professionals to ask breast cancer survivors with lymphedema whether or not they are experiencing symptoms/problems such as altered sensation in the arm, fatigue, psychological distress, and to determine if patients are decreasing their levels of physical activity. Because treatment is possible for many symptoms, it is important for patients to report any symptoms they are having to their healthcare professionals. Likewise, healthcare providers can assess for the co-morbid disease and initiate appropriate treatment or referrals. However, if these diseases are to be successfully treated, patient cooperation with recommended treatments is necessary. Patients and their healthcare providers must have frank discussions about difficult issues such as weight reduction and compliance with at-home lymphedema self-care activities. Distressed patients should also be willing to consider seeing mental health professionals if this is recommended by their therapists. It is apparent that, at times, because of the diversity of the symptoms and co-morbid conditions, a team of healthcare professionals may be needed to help breast cancer survivors with lymphedema improve their QOL.

It is hoped this article will stimulate discussion between patients and healthcare providers about lymphedema-related symptoms and possible co-morbid disease. Additionally, the need for more research into symptom and co-morbidities is critical. The combination of a more holistic approach to long-term management of lymphedema with research designed to gather more information about this understudied symptom give hope that someday, breast cancer survivors with lymphedema may live a less interrupted life.

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