

An Update on Lymphedema of the Head and Neck

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Historically lymphedema of the head and neck related to cancer and its treatment was seldom discussed or addressed clinically. Fortunately, scientists and healthcare professionals are beginning to openly acknowledge that patients with head and neck cancer who have had lymphatic disruption from tumors obstructing lymph flow, neck dissection, lymph node removal, plastic surgery reconstruction, and/or radiation treatment are at risk for developing lymphedema. European literature suggests that 30-56% of all head and neck patients develop lymphedema regardless of type of treatment,^{1,2} while a study conducted in the US found that 75% (61 of the 81) of patients who were three months or more post-treatment for head and neck cancer had some form of lymphedema.³ In all of these studies, it was noted that a larger percentage of patients having head and neck cancer developed lymphedema than those who had breast cancer. The US study was the first known study to separately evaluate both internal and external lymphedema. In the study, over half (50.8%) of the patients had combined lymphedema, six (9.8%) had only external lymphedema, and 24 (39.4%) had only internal lymphedema. These were

significant findings, as location of swelling can greatly impact the symptoms and functional difficulties experienced by these patients.

Though only one published study has examined risk factors for the development of head and neck lymphedema in patients with head and neck cancer, and more research is needed, this preliminary study identified some probable risk factors.⁴ Specifically, patients with throat tumors, multiple cancer treatment approaches, higher total dose of radiation, more days of radiation, and radiation of the surgical site had increased risk. Interestingly, no demographic or patient characteristics such as weight or age appeared to increase risk. This finding sets lymphedema related to head and neck cancer apart somewhat from breast cancer-related lymphedema where, for example, weight might increase risk. Because no modifiable risk factors have been identified and the lack of any lymphedema prevention studies in patients with head and neck cancer, prevention of the cancer itself is currently the best hope for reduction of this

problem. Since the HPV virus can cause head and neck cancer, it is very important that young boys and girls receive the HPV vaccine. Also, due to its high prevalence and treatment-related risk factors, patients undergoing treatment for cancer of the head and neck warrant close monitoring for internal and external swelling during and after treatment.

Despite the high prevalence of lymphedema of the head and neck, there is little research about the condition to date. Most information about the difficulties people with head and neck lymphedema experience comes from clinical observations by healthcare professionals who care for the patients or from patients themselves. We recently completed a four-year study that followed patients with head and neck cancer for up to 18 months post-treatment and currently have an open study evaluating yoga as a possible complementary therapeutic approach for patients with head and neck cancer, many of whom have lymphedema. Though data from these studies cannot be presented today, our close interactions with patients in these studies,

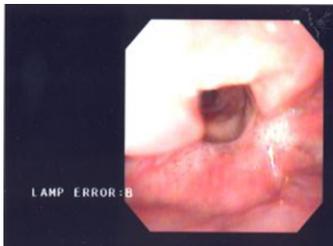


Photo 1



Photo 2



Photo 3



Photo 4

coupled with clinical management of patients with head and neck lymphedema by our team, enable us to share some of our general observations about lymphedema in the head and neck that we hope will be informative.

During the course of our four-year study, we determined that most of our patients had internal, external, and combined lymphedema. This validated the previous findings by Deng et al.⁴ We also noticed several problematic, lymphedema-related symptoms that appear to vary somewhat based upon location of the swelling. Internal swelling (photo 1) can compromise vital functions if severe. This is understandable given the restriction of space, which is easily noticed when compared to a patient without internal swelling (photo 2). Such swelling in the throat can make it hard to swallow, create a “full” feeling in the throat, cause problems with speech (hoarseness or difficulty speaking for more than a few minutes at a time), or a chronic cough. Eating and drinking may also be a problem. Internal swelling in the sinus areas can cause headaches, tooth aches, blurred vision, scalp tingling or itching, and difficulty hearing. Occasionally, patients reported feeling dizzy. Severe internal swelling can compromise breathing, causing patients to end up in the emergency room and, as noted in our previous publication, possibly need additional surgery.⁵

External swelling (photos 3 and 4) can also present serious difficulties. Swelling around the eyes can make it hard to see and interfere with daily activities such as driving. It may be very hard to move the head from side to side or up and down. External lymphedema in the head and neck area is highly visible. It can distort facial features and in some cases make someone almost unrecognizable to those they knew before the swelling began. This swelling, especially when coupled with disfiguring surgery, can lead to a severely negative body image. Individuals who have combined internal and external lymphedema can experience a combination of any or all of these problems.

Working with patients who have head and neck lymphedema can be challenging, as there are many complex issues that need to be addressed. During her work

over almost five years with patients experiencing head and neck lymphedema, Emily Galford, RN, has made the following observations: “Individuals with head and neck lymphedema can quickly become emotionally distressed and depressed. They do not like how they look, and those with highly visible swelling often develop social avoidance. They become reluctant to be seen by others, particularly in public settings such as restaurants. Patients also tell me they may have to change the type of shirts, blouses, or dresses they wear to accommodate the swelling. If the swelling is pronounced, they also have a hard time turning their head and may not be able to drive. They become sad and depressed because they feel totally out of control of their body. They often need a lot of encouragement to undergo lymphedema therapy.” Ms. Galford has also observed that “family members and caregivers also experience distress. They are scared and many have told me they do not know how to help with the swelling.”

Jennifer Doersam also worked on the project and remembered feeling concern that patients and caregivers didn’t always recognize the symptoms they were experiencing and report them to their doctors. “We saw some very severe cases of internal lymphedema that caused patients to get breathing tubes, and one even had his entire larynx removed. Often when we saw patients that exhibited or described some of the symptoms of internal swelling, such as frequent throat clearing, choking after eating or drinking, or worsening hoarseness, they weren’t at all concerned and hadn’t reported the symptoms to their doctors. We would often talk to patients and their caregivers about the types of things they should keep an eye on and report to their doctors, and even when to seek emergency care. The patient’s doctor can document whether symptoms are getting better or worse over time and recognize when testing and treatment are necessary, so it’s really important to tell them what’s going on, even if it doesn’t seem serious.”

Clearly, many head and neck cancer patients with lymphedema not only need treatment for the lymphedema, but also support to cope with the condition. Currently, there is scant research to support the effectiveness of traditional lymphedema

treatment. What research is available has reported primarily on external swelling,⁶ thus the impact of therapy on internal swelling is relatively unknown at this time. Nevertheless, based on our experience, early referral to a lymphedema therapist trained in treatment of head and neck lymphedema is critical. Since many patients are unsure about engaging in lymphedema treatment and cannot drive themselves to their treatment appointments, the importance of this treatment must be stressed to both patients and families at the time of the first referral and reinforced by every member of the treatment team.

Sometimes the critical emotional and social support for these patients can come from an engaged, supportive family member; however, most of the time, medical assistance is also necessary. The type of assistance needed varies across patients and can include rehabilitation therapy, medications to manage breathing and discomfort, and psychiatric consults or medications for depression. At times, family members and caregivers also require more formal support to deal with their issues. We have found in our clinical setting, given the critical needs of these patients and possible life-threatening consequences related to the lymphedema, that a multidisciplinary approach is essential to improving patient outcomes. For example, our clinical team is led by a medical oncologist who treats patients with head and neck cancer, fully understands lymphedema, and proactively refers patients with early swelling to a trained lymphedema therapist. Advance practice nurses, staff nurses, and social workers are also part of the team and provide valuable support to both patients and families.

Patients who do not have access to resources such as those available in our metropolitan area often go undiagnosed and cannot find treatment. This is not surprising given the lack of published information about head and neck lymphedema and the symptoms that arise with it. Physicians, other healthcare professionals, and even some lymphedema therapists are not well educated about this problem. Healthcare professionals may not realize symptoms are related to lymphedema and may fail to include referrals to lymphedema therapists in the plan of treatment. This lack of

treatment can lead to increasing difficulty with overall function, decreased quality of life, and worsening lymphedema that can, at times, be life-threatening.

Due to limited information, patients with lymphedema and their family members often must serve as their own healthcare advocates. Therefore, knowledgeable professionals caring for patients with head and neck lymphedema should make sure their patients, patients' families, and any referring healthcare professional are well educated about the condition. Educational content will vary based upon each patient's specific circumstances and needs. In general, education should include teaching patients and family how to care for lymphedema at home. Observation of the patient and/or family member's ability to correctly conduct self-care activities such as exercise and applying compression garments is a necessary part of this education. Education should also include warning signs of infection (such as redness, heat, or pain) and instruction to seek immediate medical care when breathing or swallowing becomes difficult. Therapists also need to provide instructions about when to contact them for additional treatment. Referring healthcare professionals should be updated about the patient's swelling and any symptom(s) the patient is experiencing as medical treatment is sometimes needed.

Furthermore, it is critical that there is education on the emotional distress that can arise when lymphedema occurs in the head and neck. Distorted body image along with the physical symptoms can lead patients to avoid social activities and withdraw from family and friends. Patients and families should be made aware that this distress is common and they are not the only ones who experience it. If patients do not want to be seen in public or have signs of depression such as feeling hopeless or sad most of the time, they should be encouraged to seek support and/or professional help.

In closing, we will share some final thoughts from Ms. Galford: "One of the many challenging things about head and neck lymphedema is how few medical professionals know about it. The symptoms can affect the patient's everyday living, such as reading, driving, sleeping, and

eating, and this list does not even include the emotional impact it can have. Lack of knowledge concerning this condition causes great difficulties for the patients to receive the treatment and care they need. I am thankful I am part of a team that is able to focus on this problem and ensure patients are receiving the treatment they need to have a better quality of life. My hope is that as more research is done and more becomes known about it, all patients having to live with head and neck lymphedema will receive the care they deserve."

Some organizations, clinicians, and scientists are deliberately trying to raise awareness about this highly prevalent, seldom recognized type of lymphedema. The National Lymphedema Network (NLN) is leading the way in raising awareness about head and neck lymphedema. The organization sponsored a standing room only, full-day preconference workshop at the 2104 NLN International Conference on the topic that was given by a multidisciplinary team consisting of surgeons, a radiation oncologist, scientist, lymphedema therapist, and patient with lymphedema of the head and neck. In addition, the NLN is featuring lymphedema of the head and neck in this edition of *LymphLink*, increasing knowledge about this problem. It is also important to raise awareness among the general public about lymphedema of the head and neck and encourage parents to get their children vaccinated against HPV.

If you want to learn more about lymphedema of the head and neck, you can contact the NLN or visit these websites and search for "head and neck lymphedema." These include Lymph Notes (www.lymphnotes.com), the American Cancer Society (www.cancer.org), and the National Cancer Institute (www.cancer.gov). We strongly encourage everyone to learn more about the HPV vaccine and then help educate others. The CDC website has excellent information about the vaccine at (www.cdc.gov/hpv/vaccine.html). If you find yourself dealing with an uninformed healthcare provider, you may want to refer them to these resources for some self-education.

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