Lymphedema Secondary To Treatment For Breast Cancer: A Multi-Disciplinary Approach

In 2005, under the leadership of the chief of breast radiation oncology, the Breast Center at Massachusetts General Hospital in Boston began a team approach to address breast cancer-related lymphedema. In the following articles and case studies, we plan to share our experience, outline our work to date, and illustrate what can be accomplished with a dedicated multi-disciplinary team effort. The success of working as a team has motivated us to pass this message along to others. We hope to encourage our colleagues in the field of lymphedema to consider developing a lymphedema team. We also hope to demonstrate how this framework can be applied and/or adapted to other practice settings.

Successful Management Requires a Team Approach: The Why, Who And How Of A Team

By Jean O'Toole PT, MPH, CLT-LANA

Why did we decide to create a team approach?

The many quality of life challenges that patients face following treatment for breast cancer are well documented. Lymphedema is clearly one of the major challenges for patients in whom it occurs. It can also be a significant source of distress for patients who fear its development. Four years ago, a few of us involved in the care of these patients questioned if, as a Breast Center, we were doing enough to confront this often devastating side effect of breast cancer treatment. We recognized that the needs of patients with breast cancer-related lymphedema were varied and complex, requiring the skills of different disciplines. As in many other models in medicine, we determined that this problem would likely be more effectively managed if we took a structured multidisciplinary approach to breast cancer related lymphedema. Thus, our multidisciplinary team was created with only three initial members. We agreed on the overarching goal of addressing breast cancer related lymphedema proactively, aggressively and comprehensively, and to stay focused around patient centered goals. Since its inception, our team has added members, learned and reflected on our efforts, and has continued to evolve.

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conscious effort to be inclusive. We worked to develop a network of colleagues who were passionate about organizing their efforts around this problem. Presently, the team members include the patient and their support system, colleagues from surgical, medical and radiation oncology, and certified lymphedema therapists. We consider the Cancer Center nutritionists, social workers, our Cancer Resource room staff, and representatives from the Wellness community as essential to the team effort. The Durable Medical Equipment (DME) provider is also an important member of the team.

The roles of the team members are varied and the level of involvement of team members depends on the needs of the patient. However, discussing lymphedema openly and willingly with all patients is an expectation for everyone at the Breast Center. Attention to breast cancer related lymphedema has grown in our setting. Throughout our Breast Center, it is universally recognized as a serious and real side effect that warrants ongoing monitoring and attention.

Our lymphedema team coordinator is from the department of radiation oncology and has the primary responsibility of measuring patients on the perometer, organizing and interpreting the data. Patients are measured at the time of diagnosis, post-operatively, at the completion of chemotherapy, at the end of radiation, and then every four to six months for all of their years of follow up. This has provided us the opportunity to understand the natural history of lymphedema and enabled us to embark on projects of scientific inquiry. The presence of the perometer in the Breast Center has made regular assessment of arm volume possible and efficient. It affords the patients a readily accessible tool to help address their concerns regarding edema development. Furthermore, it also accurately quantifies a readily accessible tool to help address their concerns regarding edema development. Furthermore, it also accurately quantifies the efficacy of our interventions.

The medical, surgical and radiation oncology providers of care are essential. We rely on them to rule out occult disease or a vascular event that might be responsible for new lymphedema. These physicians and nurses are in a pivotal position to refer patients for care, ensure that perometer readings are performed regularly, and communicate patients' medical considerations to the rest of the team.

The social workers assigned to the Breast Center play an essential role, providing emotional support, assisting with transportation, pursuing opportunities for financial assistance and providing a link to community resources. It is these social workers who assist patients with completing forms for financial need. They are available for ongoing psycho-social support as patients cope with their lymphedema. In situations where additional mental health services are warranted, our physicians in the Psychiatric Oncology Department become involved. Our Cancer Center nutritionists also are involved as they are able and available to counsel patients on dietary considerations. Given the association of high body mass index with lymphedema, their efforts in helping patients control their weight are invaluable.8,9

There are three certified lymphedema therapists on our main campus in Boston, and two in hospital affiliated healthcare centers located outside of the city of Boston. These five clinicians are also experienced orthopedic therapists who are capable of managing not only patients’ lymphedema, but their musculoskeletal problems as well. We have intentionally supported these staff members, enabling them to go through the lymphedema training and certification as edema therapists and placed them in strategic locations to make it easier for patients to receive care closer to their homes. In addition, with intent to increase the number of trained providers in our area, MGH Physical Therapy Service hosted the Lymphedema Certification Course on three occasions. We also have compiled a list of certified lymphedema therapists by geographical area, locally and throughout New England, which enables us to recommend qualified providers in areas more accessible for our patients who do not live near our hospital.

We rely on a licensed DME provider to measure for custom garments and bill insurances. Specifically, our clinic has experienced fitter who comes to the hospital on
a weekly basis and provides this much needed service to our patients. The Cancer Resource Room at our hospital contains booklets and books on all cancer related topics, has computers available for patient use, and a classroom. Free classes and workshops on lymphedema, exercise, nutrition and fatigue are offered daily, and members of our team participate regularly, depending on the topic.

How does the team process work?

Open and regular communication strategies enable the team to coordinate their efforts. The team meets regularly to review goals and progress and adjust plans accordingly. In between meeting times, email serves to share ideas, pose questions, obtain feedback from the surgical and nursing staff in the Breast Center as well as the lymphedema therapists. The draft was reviewed by the team and feedback from all of the Breast Center providers was incorporated. It is now available to patients in hard copy and also on our Cancer Center website.

1. A lymphedema teaching sheet was developed to provide patients with reliable information regarding risk factors and answers to frequently asked questions specifically for breast cancer related lymphedema. It was created utilizing input from the surgical and nursing staff in the Breast Center as well as the lymphedema therapists. The draft was reviewed by the team and feedback from all of the Breast Center providers was incorporated. It is now available to patients in hard copy and also on our Cancer Center website.

2. The HOPES Program (part of our patient support services), the Breast Center and an affiliated Health Club are sponsoring an eight-week Pilates Following Breast Cancer class. This is made available free of charge to our patients through a special fund from the Breast Center, which was made possible through a grant request submitted by one of the lymphedema therapists. The Pilates instructor, lymphedema therapist, social worker and a nurse practitioner from the Plastic Surgery department met and discussed any restrictions required for individuals enrolled in the class. HOPES obtained consent from the patient's surgeon and/or medical oncologist. Perometer readings will be performed pre and post class.

3. We also reach out to members of The Wellness Community who are providing exercise classes for patients, so that we can be aware of the content and feel confident about referring patients to other venues. The data from...
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the exercise trials that are evaluating the impact of exercise on lymphedema is rich and our team works to stay abreast of new developments and resources that are available for patient care:13-17

4. The social workers run several support groups for breast cancer patients and routinely include the lymphedema therapists, who come and talk with patients about lymphedema, exercise and caring for their bodies. Patient feedback has been very positive as patients with lymphedema as well as those without this condition voice appreciation that the topic is so out in the open here. They tell us that they feel comfortable and safe discussing lymphedema and asking any questions they may have. These are just some examples of the many types of interactions the team has that focus on actively working together in the effort of approaching breast cancer related lymphedema with educational and exercise opportunities. Other team projects and team efforts around patient care will be demonstrated in the following article and case studies.

Summary

A team approach is possible when even a few committed providers who are passionate about addressing lymphedema begin to work together to identify needs and develop action plans. It has been our experience that a willingness to openly discuss lymphedema very early on in the patient experience and regular respectful communication are key behaviors for success. It seems that this openness establishes a culture of recognition in the practice environment, that lymphedema is a serious problem and worthy of proactive management. Strong communication strategies allow all parties involved to remain abreast of developments regarding patient needs and also provide opportunities for growth. It has been our experience that a dynamic team evolves and expands over time, and we continue to appreciate the need for other disciplines to join in the effort.

We believe that this team concept is applicable to other causes of lymphedema, and the composition of the team will vary depending on patient populations and resources. For example, in a team dedicated to vascular edema, nutritionists and exercise physiologists may play a major role. A team working together on edema related to pelvic surgery may need to include practitioners skilled in managing pelvic floor dysfunction. Regardless of the practice setting, we encourage our colleagues around the world to partner with others in their locale to take this problem on, not just as sole practitioners, but in a collegial approach with the needs of the patient driving their efforts. It can begin as a small group, with modest goals, but we will never know what can be accomplished, unless we begin.

References


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