

A GENERAL HOSPITAL'S MULTI-DISCIPLINARY APPROACH TO BCRL

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The physical, psychological and financial burden of lymphoedema can be varied and complex. Approaching these problems in a thorough manner, involving the skills of many different providers of care offers the patient a more comprehensive plan of care than can be accomplished by a sole practitioner. The purpose of this article is to describe how a team of colleagues from multiple disciplines can work together to address breast cancer-related lymphoedema (BCRL).

Key words

Lymphoedema
Breast cancer
Multidisciplinary approach
Quality of life

Breast cancer-related lymphoedema (BCRL) poses multiple challenges for patients who experience this condition, as well as for the patients who are fearful of developing this difficult side-effect of treatment (Lee et al, 2007; Dawes, et al, 2008; Nesvold

et al, 2008; Oliveri et al, 2008; Paskett, 2008; Hayes et al, 2009). The profound emotional toll, impact on body image, functional compromise and burden of management have all been well documented (Beaulac, et al, 2002; McWayne, 2005; Ridner, 2005; Ahmed et al, 2006; Jager et al, 2006). In 2005, the chief of breast radiation oncology and one

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of the lymphoedema therapists at the authors' hospital, had several conversations, questioning if, as a large breast centre, enough was being done. It was determined that this problem was not being addressed aggressively enough, prompting a process to effect change. It is the purpose of this article to share the experience of creating a multidisciplinary team approach to BCRL that has evolved over the last five years at the Massachusetts General Hospital (MGH).

The authors agreed that the mission of the lymphoedema studies team at their hospital would be commitment to the following:

- ▶ Early detection by screening for subclinical BCRL and ongoing surveillance
- ▶ The necessity to have a measurement at baseline before any cancer treatment
- ▶ Empowering patients to manage their lymphoedema with as little burden as possible and to keep their goals central to decision-making
- ▶ Contributing to the scientific literature regarding evaluation and management of BCRL.

It was decided that a network of committed providers would be created who were passionate about this problem and who would be willing to work collaboratively to carry out the mission and achieve shared goals. Today, the core team consists of representatives from radiation oncology, medical oncology, surgical oncology, physical therapy, an oncology nurse practitioner, as well as a lymphoedema programme manager and a clinical research coordinator. An extensive network of other providers who play important roles in caring for patients has also been developed. This network includes social workers, nutritionists, the wellness community (such as support groups, Tai Chi

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and yoga instructors, community exercises classes, etc). It also includes experienced fitters of compression garments and lymphoedema therapists who live geographically closer to a patient's home or work (Figure 1).

Early detection and ongoing surveillance

To accomplish this objective, a horizontal model perometer, manufactured by Pero Systems, Wulpert, Germany was adopted. The perometer has been used in the breast centre since 2005 (Petlund, 1991; Tierney et al, 1996; Stanton et al, 1997). The clinical research team has the responsibility of measuring patients and maintaining the computer database. Screening for lymphoedema begins immediately following initial diagnosis, before surgery (baseline). Newly-diagnosed patients are also provided with an information sheet describing lymphoedema as well as the perometer. Establishing pre-operative data is imperative as patients often present with volumetric asymmetry at baseline. Because patients can normally be asymmetrical, it is difficult to interpret postoperative change without knowing their baseline measurement. In a sample of the authors' breast cancer patients

(250) measured preoperatively, over 20% revealed a volume difference of >5%, and many other patients demonstrated even larger differences, even as high as 18%, emphasising the importance of this preoperative measurement.

As the financial burden of caring for lymphoedema is an ongoing problem for many patients, the social service helps patients to find resources.

This baseline measurement provides a framework for evaluating postoperative change and has been reported by several authors (Harris et al, 2001; Clark and Harlow, 2005; Stout Gergich et al, 2008). Patients are measured preoperatively, postoperatively, after chemotherapy, after radiation and then at 4–6-month intervals for the duration of their care at the clinic.

The perometer provides reliable and efficient data to assess the efficacy of treatment intervention. The measurements are entered within

the electronic medical record of the hospital for all healthcare professionals to view as they care for the patient. Perometer readings of concern are reported to healthcare professionals to inform them of changes in a patient's status, and facilitate timely changes in plans of care if needed.

The number of patients captured at baseline has continued to increase annually at MGH since 2005. Currently, MGH has 1,574 patients with baseline arm volume measurements. These baseline patients are re-measured and evaluated every four to six months. Additionally, there are over 460 patients who do not have a baseline measurement that are monitored for changes in their arm volume. The absence of a baseline measurement in these patients is commonly the result of patients transferring their care to MGH following initial breast cancer surgery or treatment, or a history of breast cancer that predates the perometer.

Empowering the patient

The lymphoedema studies team worked together to create a patient education sheet on BCRL. It includes the authors' answers to questions frequently asked by patients. By doing this project as a collaborative effort, patients were provided with a balanced message about risk factors, signs and symptoms that reflected the consensus of the Breast Centre. A consistent message we try to impart to patients is that the goal of our interventions is to reach their desired level of function. The need to exercise as a management strategy for controlling oedema, weight, bone health, and all of the other physiological and psychological benefits that are well documented in the literature are emphasised (Cheema et al, 2006; Cheema et al, 2008; Ahmed et al, 2008; Knobf et al, 2008; Hayes et al, 2009; Sagen et al, 2009; Schmitz et al, 2009).

To this end, the team found funding for exercise classes for breast cancer patients at the health club affiliated with MGH. These courses provide patients

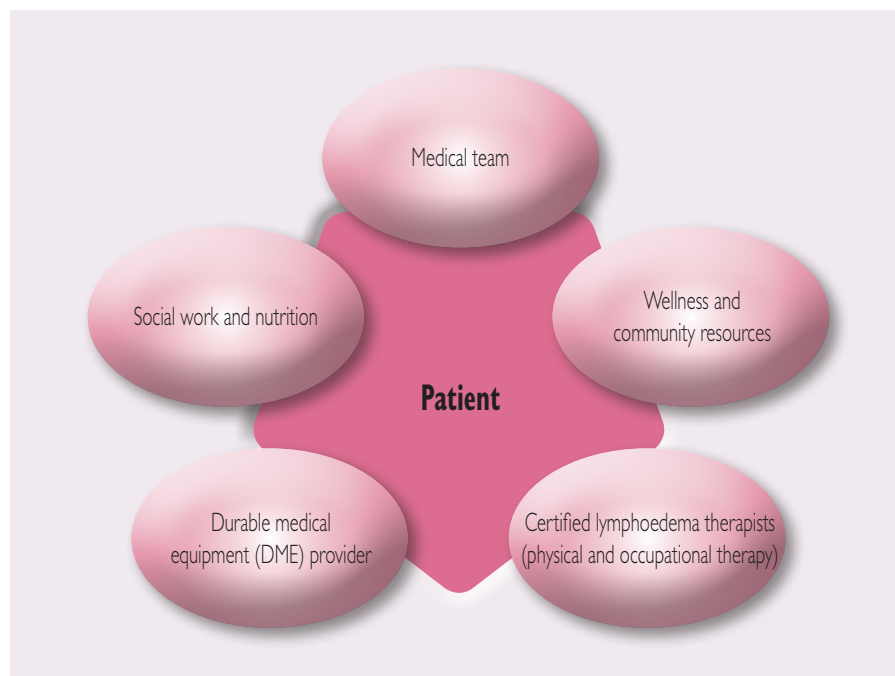


Figure 1: Members of a multidisciplinary team focusing on the patient as the central and pivotal member of the team.

with the opportunity to experience exercise in a safe environment, with the hope that it will also establish the motivation to continue on the conditioning or exercise programme of their choice. Before establishing the course, the trainers at the health club met with therapists and nurses at the hospital to develop a gentle and progressive exercise regimen. If weight loss is a particular problem that the patient is struggling with, nutritionists become involved as well.

Other team initiatives to empower patients include support groups run by social workers who work on the breast team. These colleagues also have their offices in the breast centre and are available to patients. As the financial burden of caring for lymphoedema is an ongoing problem for many patients, the social service helps patients to find resources. Furthermore, a grant from the Friends of the MGH Cancer Center helps to provide compression garments for patients who do not have insurance benefit to cover their costs.

To help patients who live in remote areas, a resource list has been created, including therapists and facilities located not just throughout Massachusetts but in all of the New England states. This list is updated twice a year. Recognising that there are areas underserved by healthcare professionals, the team at MGH also sponsor lymphoedema therapy certification courses to increase the pool of qualified therapists available in the community.

Contribution to scientific literature

Recognising that there are many unanswered questions in the field of lymphoedema management, and given the lack of evidence-based research, a primary goal is to continue to contribute to the body of literature dedicated to this condition. The team structure and support described in this article has resulted in funding for a large prospective, controlled, randomised intervention trial that will screen around 2,500 women over a five-year period. The trial opened in

August of 2009. In addition to the perometer measurements, data on function, symptoms, quality of life and fear avoidance behaviours, as well as information regarding air flights, blood draws and blood pressure will be taken. Patients will be randomised for intervention when their volume difference exceeds a 5% relative volume change, as compared to the baseline measurement. The rationale is whether or not early intervention can prevent progression of lymphoedema. The trial design also provides the opportunity to track the natural history of cording or what has been also called

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axillary web syndrome (Moskowitz et al, 2001; Leidenius et al, 2003; Leduc et al, 2009; Torres et al, 2009).

A recent collaborative effort with the vascular medicine department to pursue non-invasive imaging in a small pilot sample is in progress. The purpose of this initiative is to study the efficacy of vascular imaging for determining the pathophysiology of cording. A protocol that would allow the team to study the impact of exercise in patients treated for breast cancer is also planned.

It is the authors' goal that the information gained from the five-year trial will provide invaluable insight into determining the level of symptoms, functional disability, and changes in quality of life that breast cancer patients experience due to changes in their arms which results from treatment. Furthermore, it is hoped that this data will be used to support the belief that impairments in the upper extremities result in functional

disability and greatly diminishes quality of life.

In an attempt to standardise the variety of methods used to distinguish changes in arm volume, a mathematician/statistician from the department of radiation oncology has created an equation to determine the relative volume change (RVC) of the patients affected arm. This equation provides the opportunity to evaluate change in the affected (ipsilateral to cancer therapy) arm as compared to the baseline measurement (controlling for baseline asymmetry), and controlling for changes bilaterally.

Conclusion

The authors' experience of working as a team has shown that the varied challenges of BCRL can be managed more successfully by the dedicated effort and differing skills of colleagues from many backgrounds than they can by working in isolation. This could be a useful model not just for BCRL, but for any patient population who suffer from this problem.

The make up of such teams will be different depending on the venue and the resources available, but it can easily begin as a grassroots effort between two colleagues who share a vision and have an awareness of the scope and the needs of their particular patient population. By achieving the initial goal of creating an appreciation in your clinical setting that lymphoedema is a real problem and that a proactive approach is ideal, your team can be well on its way. You should work out the needs of the patient population and clarify your mission. As you identify your available resources and establish preferred mechanisms for referral the team will grow. Team members should agree on strategies for communication as well as the frequency of meetings to review progress, goals, projects and plans (Salas et al, 2008). As teams evolve over time, projects may change, but remaining true to the mission is imperative and remains the cornerstone of how the network functions.

Approaching the problem of BCRL as a multidisciplinary team has been an extremely gratifying experience. The presence of the team in the Breast Centre at MGH has effected a change in the culture, so that now there is universal appreciation of the need to openly and proactively confront this troubling and often serious side-effect of treatment. Early identification has allowed us to begin early intervention before oedemas become large or longstanding. The contributions from other services (social service, wellness, nutrition, etc.) have been important additions to the care of this patient population. Patients are appreciative that their goals and values are considered, respected and integrated into an agreed upon plan of intervention, and the availability of the perometer is a service they greatly value. It is hoped that other colleagues will consider building a multidisciplinary team suitable for the needs of their patient population, and that they will experience similar results to those achieved at MGH. JL

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Key points

- ▶▶ The quality of life challenges of breast cancer-related lymphedema (BCRL) are varied and complex.
- ▶▶ Successful management involves the contributions of team members from many disciplines.
- ▶▶ Preoperative assessment and ongoing surveillance are essential.
- ▶▶ Lymphoedema interventions should be centred around the patient's goals.
- ▶▶ Commitment to contributing to the scientific literature is an essential team responsibility.