

# IMPLEMENTATION OF A BCRL MANAGEMENT PROGRAMME

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## Abstract

**Background:** Breast cancer-related lymphoedema (BCRL) is a growing concern with the increased survival rate following breast cancer (Smith et al, 2011). However, limited data is available on prospective management designed to reduce the morbidity of BCRL. **Aims:** To evaluate the impact of the development of a BCRL programme on the management of women with breast cancer. **Methods:** In 2004, a BCRL programme was developed at William Beaumont Hospital (WBH) to increase awareness regarding BCRL and to have more patients evaluated by a BCRL expert prospectively. Indications for patient referral and therapies recommended were evaluated and compared during a five-year time period. **Results:** At inception, the majority of cases seen in the clinic focused on existing BCRL (86%), with no patients seen electively (91% of all patients presented with clinically evident lymphoedema). Five years after inception, 25% of all new breast cancers diagnosed at WBH were seen electively in the clinic and significantly more were seen for elective evaluation (18.9% v. 0%,  $p < 0.001$ ). **Conclusions:** Five years following the inception of a BCRL clinic, significant increases in elective BCRL visits were seen. **Declaration of interest:** None.

## Key words

Lymphoedema  
Breast cancer  
Prevention  
Multidisciplinary care

The incidence of breast cancer in the United States is approximately 200,000 cases per year, with an estimated prevalence of 2.4 million women (Jemal et al 2007; Desantis et al, 2011). As early detection and improved therapies result in

increased long-term survival of women with breast cancer (Smith et al, 2011), management of the side-effects of cancer treatment assumes increasing importance. Currently, up to 800,000 women have some form of breast cancer-related lymphoedema (BCRL), based on incidence and prevalence

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rates of breast cancer and averaged rates of BCRL (Lawenda et al, 2009). Estimates of incidence and prevalence of BCRL are highly variable due to significant discrepancies in reported incidence rates of BCRL from 2% with lumpectomy alone, to 65% with axillary lymph node dissection and radiation therapy (Mazeron et al, 1985; Lawenda et al, 2009; Gartner et al, 2010).

BCRL can lead to physical, emotional, and psychological challenges, and is a constant and devastating reminder of breast cancer and the treatments incurred (Towers et al, 2008). Other sequelae and side-effects can also occur after the local and systemic management of breast cancer which may exacerbate the distress of BCRL, including shoulder dysfunction, muscle tightness, restricted range of motion, as well as axillary cording and webbing (Ewertz and Jensen, 2011; Harrington et al, 2011). In the authors' opinion, there is currently limited data available regarding programmes designed to address both BCRL and the other morbidities of breast cancer treatment. This is likely to be due to a number of factors, including a lack of prospective randomised trials and divergent assessments and therapeutic paradigms across healthcare institutions.

In conjunction with the Beaumont Cancer Institute, the Breast Care Center at William Beaumont Hospital, Royal Oak, Michigan established a lymphoedema clinic in 2004 to evaluate and treat women with these conditions.

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The purpose was to use education and early management techniques to:

- ▶ Decrease the incidence of BCRL and related post-treatment complications
- ▶ Diagnose BCRL at the subclinical and early stages of the disease in order to avoid its chronic complications, such as infection, chronic pain and impaired function of the affected arm
- ▶ Educate referring clinicians (including primary care doctors, breast surgeons, medical oncologists, and radiation oncologists) on the goals and outcomes of early, proactive BCRL management.

This analysis reviews the implementation of the programme and referral outcomes in the following five years.

### Materials and methods

The three most prominent barriers that limit patient participation in cancer programmes have been seen as being:

- ▶ Institution-related, i.e. lack of dedicated personnel to triage patients, lack of resources to help patients without means of seeking care independently
- ▶ Patient-related, i.e. financial limitations, lack of information and social support
- ▶ Physician-related, i.e. lack of knowledge regarding programmes, lack of information about the topic (Albain et al, 2009).

When constructing the William Beaumont Hospital lymphoedema programme, these factors were directly addressed to increase access and entry into the programme. The most common barrier cited is related to a lack of awareness of a programme's availability for both healthcare professionals and patients (Mills et al, 2006; Albain et al, 2009). Therefore, both a comprehensive educational and marketing strategy for healthcare professionals and patient education were the main focus at the inception of the clinic.

Healthcare professionals were educated through multiple, directed

interventions. The first was the development of brochures targeting clinicians. Their purpose was to raise awareness of the programme, so that even those who were only peripherally involved with breast cancer management, but who had access to patients with BCRL, had a resource to offer their patients. The brochures educated physicians on BCRL (incidence, management

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techniques), discussed the William Beaumont lymphoedema programme (consultations, therapeutic measures), and provided contact information for clinicians and their patients. Oncologists were specifically targeted through the breast cancer tumour board, which is held weekly. This meeting of breast surgeons, medical oncologists, radiologists, pathologists, and radiation oncologists provided a forum to discuss the programme.

Initially, participating clinicians were provided with an introduction to the programme along with potential schema for patients to be directed into the programme (i.e. the flow of the clinic, including diagnostics, therapeutics and follow-up protocols). The details included were the diagnostics utilised, treatments offered, and treatment paradigms (criteria for patients receiving prophylactic treatment with sleeves, when sleeves would be used as therapy, when therapy would include complex decongestive physiotherapy) that would be employed. To increase familiarity and comfort with the programme, anyone at the tumour board could comment on potential problems that could limit referral. This 360-degree evaluation method

was used so that clinician barriers to referrals could be acknowledged and incorporated into the planning of the clinic.

Patient education focused on informing women about BCRL and letting them know that even without overt symptoms, elective evaluation could still provide a benefit by reducing more severe symptoms and progression of lymphoedema (Stout Gergich et al, 2008). Information was given about the causes of lymphoedema and ways to prevent its development. A lecture series was offered so that patients and their families could receive verbal and written teaching even before they underwent surgery. Importantly, as clinicians managing these patients had been educated on BCRL, increased discussions regarding BCRL took place between breast surgeons, medical oncologists, and radiation oncologists and their patients.

Once enrolled in the programme, patients were managed by a dedicated rehabilitation specialist (physician) trained in lymphoedema detection and management. Education was an essential component of these sessions. Lymphoedema was diagnosed primarily using the circumferential measurement technique with measurements taken in both limbs, with the unaffected limb serving as a control. Measurements were taken at reproducible points: for BCRL patients, measurements were taken at the olecranon process and then 10cm proximally and distally. After evaluation, women with BCRL, or at high risk of developing it, were prescribed interventions consisting of complex decongestive physiotherapy, graduated compression devices, manual decongestive massage therapy, as well as stretching and strengthening exercises. Prompt intervention for complications arising from lymphoedema was readily available in an effort to minimise additional tissue damage. All of this care was provided in a supportive environment, focusing on the needs of the breast cancer patient and their family.

**Table 1**

**2004–2005 patient characteristics**

	2004–2005 (n=87)
<b>Presentation</b>	
Lymphoedema/prophylaxis	75 (86.2%)
Shoulder/rotator cuff	10 (11.5%)
Radiculopathy	1 (1.1%)
Mastodynia	1 (1.1%)
<b>Age (mean)</b>	59.6 (13–90)
<b>Gender</b>	83 female (95.4%) 4 male (4.6%)
<b>Tumour site</b>	
Breast	77 (88.5%)
Gynaecological	3 (3.4%)
Soft tissue	2 (2.3%)
Other	5 (5.7%)
<b>Treatment</b>	
Lymph nodes removed Mean/median (range)	15/14 (0–43)
Chemotherapy	52 (59.8%)
Radiation therapy	63 (72.4%)

**Table 2**

**2004–2005 treatment allocation**

	2004–2005 (n=87)
<b>Clinical lymphoedema at presentation</b>	79 (90.8%)
<b>Lymphoedema treatment prescribed</b>	
CDP	52 (69.3%)
Sleeve	15 (20%)
Other	4 (5.3%)
None	4 (5.3%)

To remove institution-related barriers, patients who received treatment through the Breast Care Center at William Beaumont Hospital were provided with information on the lymphoedema programme throughout their care, which increased the number of patients exposed to the programme and potentially increased referrals.

To evaluate the efficacy of the programme, an audit of new cases seen during the first 15 months of the programme from 2004–2005 was performed, evaluating the number of patients, presenting patient and treatment characteristics, and therapeutic modalities utilised. Data were collected on the number of

patients with breast cancer (all stages) evaluated at William Beaumont Hospital based on data collected in a prospective National Comprehensive Cancer Network (NCCN) database for 2009–2010. This data was cross-referenced with hospital billing records that allowed for the determination of the number of new consultations in the breast cancer lymphoedema clinic. Further, billing codes and records were assessed to determine the most common diagnoses seen in these patients. Chi-square tests were utilised to analyse the difference in presentation patterns. A p-value of 0.05 or less was considered statistically significant.

**Results**

**Initial implementation**

Patient characteristics for the new consultations seen in the lymphoedema clinic over the first 15 months (2004–2005) following its inception are presented in *Table 1*. Of the new consultations seen, approximately 60% of patients received chemotherapy and 72% received radiation therapy in addition to surgery. Initially, the clinic was open to all forms of cancer-related lymphoedema (accounting for a small number of non-BCRL cases). Patients without BCRL were referred to other lymphoedema experts shortly after the start of the clinic.

At the inception of the clinic, the majority of patients presented with a primary complaint of lymphoedema (86.2%), with the second most common complaint being related to shoulder/rotator cuff complaints (11.5%). 95.4% of patients were female due to a preponderance of breast and gynaecological cancers, 88.5% and 3.4% respectively. Of the 87 patients initially presenting to the clinic, none were diagnosed with subclinical disease or presented electively for BCRL prevention. Overall, 90.8% of all patients seen had clinically evident BCRL at presentation. Of the 75 patients presenting with a primary complaint of lymphoedema, the majority were managed with complex decongestive physiotherapy (CDP) (69.3%), while those with less severe

lymphoedema were managed with compression sleeves (20.0%) (Table 2).

With regards to shoulder dysfunction, 24 patients (27.6%) had decreased range of motion at presentation, while 65 (74.7%) had some form of shoulder weakness. The majority of these patients (n=56, 86.2%) were managed with a combination of home stretching and strengthening exercises.

#### Five-year impact

Five years after the inception of the clinic, a total of 622 patients had been seen between 2009 and 2010. Of these patients, 308 patients were seen in the clinic in 2009 and 314 were seen in 2010. Over the same time period, 1016 patients presented to the Breast Care Center for initial evaluation. Overall, significantly more patients were seen for elective counselling from 2009–2010, compared to the inception of the clinic (18.9% v. 0%,  $p<0.001$ ). In addition, more patients were seen for primary shoulder complaints (30.7% v. 11.5%,  $p<0.001$ ), while less patients were seen for primary lymphoedema complaints (33.8% v. 86.2%,  $p<0.001$ ). Overall, of the 1016 initial consultations seen in the Breast Cancer Center from 2009–2010, 228 were subsequently evaluated in the lymphoedema clinic for a new consultation rate of 22.4%. Further analysis found that in 2009, 23 patients (23% of new consults, 3.7% of all breast care centre consultations) were seen for elective counselling, while 77 presented with a post-treatment complaint (77% of new consults, 12.3% of all breast care centre consultations). The number of patients presenting for elective counselling in 2009 was significantly higher than at the inception of the clinic (23% v. 0%,  $p<0.001$ ). Of the 77 patients presenting with post-treatment morbidity, only 26 were seen primarily for BCRL (33.8%) while the majority were seen for other breast cancer treatment-related conditions including mastodynia, adhesive capsulitis, rotator cuff pathology, soft-tissue pain, and mono-neuritis.

In 2010, 20 patients (15.6% of new consults, 5.1% of all breast care centre consultations) were seen electively, while 108 patients presented with various post-treatment complaints (84.4% of new consults, 27.7% of all breast care centre consultations). The number of patients presenting for elective counselling was significantly higher in 2010 than at the inception of the clinic (15.6% v. 0%,  $p<0.001$ ). Of the 108 patients, 31 were

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seen primarily for BCRL (28.7%), while the majority were seen for treatment-related conditions including mastodynia, adhesive capsulitis, rotator cuff pathology, and mononeuritis of the upper limb.

#### Discussion

The purpose of this analysis was to examine the efficacy of implementing an education-oriented BCRL programme within a hospital system and to assess outcomes of the programme five years after its inception. Unfortunately, few comparable programmes are available for comparison. Minimal data have been published on the development of lymphoedema clinics that incorporate management of BCRL with or without prospective surveillance (Lee et al, 2001; Garfein et al, 2008). Nonetheless, several relevant observations can be drawn from this analysis. First, education-oriented programmes can lead to a significantly increased number of patients being seen for elective management of BCRL, rather than patients presenting when clinically symptomatic. At the inception of the programme, none of the initial 87 patients assessed in the clinic presented for elective management or with sub-clinical disease. After five years,

approximately 19% of all new consults and 7% of all breast care centre consultations were seen for elective management. Furthermore, within five years of the inception of the clinic, approximately 25% of all new breast cancers diagnosed within the authors' hospital system were being seen in the lymphoedema clinic. Using an estimated incidence of BCRL of 15% based on multiple series, the expected number of BCRL cases would be 94 and 59 cases in 2009 and 2010 respectively (Mazon et al, 1985; Lawenda et al, 2009; Gartner et al, 2010). Within the same time period, 57 patients were seen in the clinic for BCRL and another 43 patients were evaluated electively. This represents 65.4% of cases (based on the 15% estimate) being referred, which is significantly higher than traditional values of 35% of BCRL patients being referred for evaluation (Lee et al, 2001).

The value of increasing the number of patients seen electively and in the early phases of BCRL has been demonstrated by prospective data from the National Institutes of Health (NIH) study, which showed that the use of compression sleeves in patients with sub-clinical BCRL led to excellent results with minimal morbidity (Stout Gergich et al, 2008). Evaluating patients electively allows for the diagnosis of sub-clinical BCRL using techniques such as bioimpedance spectroscopy. This can potentially result in less aggressive management techniques and in the possible prevention of the chronic morbidities associated with BCRL (Ward et al, 1992; Ward, 2006). Since early identification and conservative treatment of BCRL may inhibit its progression to more advanced stages, costly and labour-intensive physical therapy and/or compression pumps may be avoided. A recent study published by Shih et al (2009) evaluated over 1,800 breast cancer patients, with a cost analysis finding an increase of \$8,000–\$11,500 in annual cost in breast cancer survivors treated for BCRL versus a similar cohort without BCRL. Therefore, utilisation of improved diagnostic modalities and elective visits

may facilitate earlier clinician detection (during the sub-clinical phase) and management of BCRL, and have the potential to reduce associated costs.

The second conclusion that may be derived from this analysis is that while BCRL is a common morbidity associated with treatment of breast cancer (approximately 30% in the authors' series), other complaints, including shoulder dysfunction and pain are extremely common. Recent analyses have found that up to 35% of patients undergoing treatment for breast cancer develop restrictions in arm and shoulder movement (Ewertz and Jensen, 2011; Harrington et al, 2011). Arthralgia, neuropathic pain, and carpal tunnel syndrome have also been associated with the development of BCRL; further, these complications have been associated with patients receiving hormonal therapy and chemotherapy (Sestak et al, 2009; Norman et al, 2010). Hormonal therapy and chemotherapy were routinely administered to the authors' patients and, as such, these were common complications seen in the clinic (Sestak et al, 2009; Din et al, 2010). These complications were managed pharmacologically and by directed therapy. This further highlights that clinics designed to address post-breast cancer treatment morbidities need to focus on more than just BCRL if they are to be effective in addressing the needs of the patient population.

The final conclusion that may be drawn from this study is that in patients presenting with clinically diagnosed BCRL, CDP is still the predominant method of treatment. This therapy represents a combination of various techniques including compression, manual lymphatic drainage (MLD), skin care, and exercises administered by well-trained therapists. CDP consists of two phases of treatment.

In phase I, management takes place in an outpatient setting with a multi-week programme of MLD, short-stretch compression bandaging, exercise, and proper skin and nail care

administered by trained therapists. Phase II represents maintenance at home and involves skin care, exercise, self-massage, and use of compression. The efficacy of CDP has been verified in multiple studies. Vignes et al (2007) evaluated 537 patients who received CDP and identified a change in mean arm volume from 1,054 +/- 633 cc before CDP to 647 +/- 351 cc

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following CDP. These data have been validated by multiple series which identified improvements in quality of life (QoL) and up to 70% decreases in excess arm volume with CDP (Liao et al, 2004; Kim et al, 2007; Karadibak et al, 2008).

Currently, limited data exists comparing CDP to more traditional therapeutic modalities, such as compression garments alone, manual lymphatic drainage (MLD) and medications. Didem et al (2005) compared CDP with standard therapies in 53 patients and found CDP to significantly improve BCRL and increase shoulder mobility.

There are limitations to the current analysis. This review was performed retrospectively. Although initial clinic patients were prospectively entered into a database, subsequent analyses were performed retrospectively. In addition, no direct measurements of BCRL were analysed in the data with the coding of BCRL based on clinical assessment and CDP coding rather than diagnostic assessments. Lastly, clinic measurements were performed using arm circumference;

**Key points**

- ▶▶ BCRL is an increasingly important issue with breast cancer survivors due to improved survival and increased utilisation of multi-modality therapy.
- ▶▶ Limited information is available detailing the development of hospital-based BCRL programmes designed to assess and treat patients prophylactically and sub-clinically.
- ▶▶ Results from the authors' institution demonstrated that with the advent of an education-oriented programme, increasing numbers of patients were evaluated prophylactically.
- ▶▶ As the programme developed, it became clear that future programmes should address other chronic issues besides BCRL, including shoulder dysfunction and neuropathy.

the authors have currently switched to more sensitive equipment including bioimpedance spectroscopy to improve their ability to diagnose BCRL at the sub-clinical/early stages of the disease.

In the authors' opinion, there are few recommendations for the management of BCRL diagnosis and management. There are no National Comprehensive Cancer Network (NCCN) recommendations at this time on diagnostic modalities, treatment, or the role of elective management of BCRL in high-risk patients in the current breast cancer guidelines (2011). The American Cancer Society provides guidelines on risk reduction and management, but with few evidence-based guidelines presented (2011). Going forward, the goal of the authors' lymphoedema

clinic is to create evidenced-based guidelines to create diagnostic and treatment paradigms and strategies. An example of this can be noted from the lymphoedema clinic at Beth Israel Deaconess Medical Center, where a diagnostic schema was devised based on the probability of lymphoedema ascertained from patient history and physical examinations, with subsequent diagnostic modalities including lymphoscintigraphy (Garfein et al, 2008). Following guidelines from the National Lymphedema Network (NLN, 2011), the authors' institution has developed guidelines based on their initial experiences that incorporate pre-treatment risk reduction counselling, pre- and post-treatment measurements of both arms with consistent techniques and thresholds, and documentation of measurements and therapeutic measures instituted.

## Conclusions

Implementation of an education-oriented BCRL programme led to an increase in the referral of patients for elective management and an increased percentage of breast care centre consultations referred for BCRL. In patients with a clinical diagnosis of BCRL, the primary method of management remains complex decongestive physiotherapy. JL

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