Self-Management Strategies for Malignant Lymphedema: A Case Report with 1-Year and 4-Year Follow-Up Data

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ABSTRACT

Purpose: Malignant lymphedema is an accumulation of interstitial fluid caused by tumour infiltration or compression of lymphatic vessels. Our objective is to describe self-management strategies for malignant lymphedema using a case report. **Client Description:** A 50-year-old woman with advanced breast cancer was referred to our centre with a 3-month history of unexplained left-arm edema, subsequently diagnosed as malignant lymphedema caused by tumour compression of the axillary lymph nodes. **Intervention:** She undertook a physiotherapist-guided, modified lymphedema treatment programme, with self-management interventions including self-bandaging and exercise. Limb volumes and leisure exercise levels were measured over a 1-year period. Data were collected from her follow-up visit 4 years post-diagnosis of lymphedema. **Measures and Outcome:** Within the first month, the patient's excess limb volume reduced from 26.8% to 5.9% and, 1 year later, remained stable at 3%. Over time, her exercise levels increased (1-year follow-up: 33.5 MET-hours per week). At 4 years, her excess limb volume was 9.7%, and exercise levels were at 36 MET-hours per week. **Implications:** A woman with moderate malignant arm lymphedema caused by advanced breast cancer successfully adhered to a guided self-management programme and benefited from reduced swelling and improved self-reported physical function in the long term. This case provides oncology health professionals with knowledge about self-management options for malignant lymphedema.

Key Words: breast neoplasms; exercise; lymphedema; self-care.

RÉSUMÉ

Objectif : le lymphœdème malin désigne une accumulation de liquide interstitiel causé par l'infiltration d'une tumeur ou la compression des vaisseaux lymphatiques. Les auteurs utilisent un rapport de cas pour décrire des stratégies d'autogestion du lymphœdème malin. **Description de la cliente :** une femme de 50 ans atteinte d'un cancer du sein avancé a été dirigée vers le centre des auteurs parce qu'elle présentait un œdème inexpliqué du bras gauche depuis trois mois. Cet œdème a ensuite été diagnostiqué comme un lymphœdème causé par la compression d'une tumeur sur les ganglions axillaires. **Intervention :** la patiente a entrepris un traitement modifié du lymphœdème, orienté par des physiothérapeutes et comportant des interventions d'autogestion, y compris les changements de bandages et des exercices. Les auteurs ont mesuré le volume des membres et le taux d'exercices de loisir sur une période d'un an. Ils ont recueilli les données jusqu'au rendez-vous de suivi quatre ans après le diagnostic de lymphœdème. **Mesures et résultats :** au cours du premier mois, le volume excédentaire du membre de la patiente est passé de 26,8 % à 5,9 % et était demeuré stable un an plus tard, à 3 %. Au fil du temps le taux d'exercice de la patiente a augmenté (suivi d'un an : 33,5 équivalents métaboliques de l'effort [MET]-heures par semaine). Au bout de quatre ans, le volume excédentaire de son bras était de 9,7 %, et son taux d'exercice, de 36 MET-heures par semaine. **Conséquences :** une femme présentant un lymphœdème malin modéré du bras causé par un cancer du sein avancé a suivi un programme d'autogestion orienté et observé une diminution de son œdème et une amélioration autodéclarée de sa fonction physique à long terme. Ce cas fournit aux professionnels en oncologie de des connaissances sur les possibilités d'autogestion du lymphœdème malin.

Lymphedema is an abnormal accumulation of protein-rich interstitial fluid due to obstruction, trauma, or developmental abnormality of the lymphatic system.¹ It is estimated that more than 20% of women develop upper limb lymphedema after being diagnosed with breast cancer.² Common risk factors for cancer-related lymph-

edema include surgical resection of the lymph nodes, radiation-induced lymph node fibrosis, obesity, and age.^{2,3} Less well recognized is malignant lymphedema, which is caused by direct tumour infiltration or compression of the lymphatic vessels.⁴ Malignant lymphedema is often characterized by the rapid onset and progression of edema

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and may be associated with skin changes and general weakness.⁴ This is prevalent in people with advanced or metastatic cancer, and studies have reported that as many as 85% of individuals at the end of life may be affected by edema of various causes.^{5,6}

Important effects of lymphedema include swelling in the limbs and other areas because of the accumulation of fluid and increased susceptibility to infections because of impaired lymphatic function. Lymphedema has been found to have negative effects on psychological well-being, upper extremity function, and quality of life in women with breast cancer.^{7,8} Chronic edema has also been found to be associated with recurrent infections, hospitalizations, and time off work.⁹

Complete decongestive therapy (CDT), the standard treatment for lymphedema, consists of two phases. The reductive phase involves 24-hour, multilayer compression bandaging, daily manual lymphatic drainage, remedial exercises, and skin care under the care of a certified lymphedema therapist. Once maximum edema reduction is obtained, the maintenance phase includes daily compression (daytime custom-made or standard garment and nighttime bandaging or garment), self-massage, exercise, and skin care to control the lymphedema. CDT, particularly compression therapy, has been found to be effective in the treatment of lymphedema, including cases of malignant lymphedema.^{10–12} Unfortunately, lymphedema is a lifelong, irreversible condition, and managing it can be costly and time consuming.¹⁰ Even with daily interventions, frequent therapist appointments, and expensive compression materials, patients may be unable to fully comply with the demands of traditional CDT.

Barlow and colleagues¹³ have defined *self-management* as

the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established. (p.178)

Educating patients about self-management strategies, such as self-massage, skin care, compression garments, and exercise, may be valuable in helping them to successfully control their lymphedema.¹ Exercise programmes have been found to be effective for people with lymphedema,^{14,15} but other self-management strategies have been less explored in the literature.^{16,17} In their review, McNeely and colleagues¹¹ found moderate evidence supporting the use of compression garments and bandaging in managing lymphedema. Tidhar and colleagues¹⁸ studied 30 participants in a self-bandaging programme; they found significant improvements in lymphedema

volume, and patients reported satisfaction and feelings of being in control.

Little is known about self-management interventions for complex types of lymphedema, including malignant lymphedema. In this article, we present a unique case of a motivated woman with malignant lymphedema successfully adhering to a modified CDT programme with an emphasis on self-management strategies. This case may help guide health professionals working with the lymphedema patient population. Our objectives are to (1) describe self-management strategies for malignant lymphedema using a case report and (2) raise awareness of the diagnosis and treatment of malignant lymphedema in the oncology setting. The authors obtained informed consent from the patient to publish this case report.

CLIENT DESCRIPTION

A 50-year-old, right-handed woman, Mrs. C., was diagnosed in February 2012 with cancer of the left breast, which had spread to the ipsilateral axillary lymph nodes. She commenced chemotherapy with paclitaxel and trastuzumab, with no planned surgery or radiotherapy. In June 2012, she was referred to our specialized hospital-based lymphedema clinic with a 3-month history of unexplained left-arm edema, which she reported was worsening over time. This was subsequently diagnosed by a specialized physician as malignant lymphedema caused by tumour compression of the axillary lymphatic structures.

On assessment, the left upper limb had a positive Stemmer sign, and the lymphedema was classified as moderate in severity (26.8% excess volume).¹⁹ Mrs. C. reported avoiding any use of her left upper limb for her daily activities, such as cooking.

INTERVENTION

Modified complete decongestive therapy programme

We immediately initiated a modified CDT programme, with an emphasis on self-management interventions, with Mrs. C. at the hospital outpatient physiotherapy department. The programme was delivered under the guidance of a physiotherapist certified in lymphedema therapy. Self-management strategies are described in Table 1.

Initially, we scheduled therapist follow-up visits every week to track limb measurements and review self-management strategies as needed. After 4 months, as a result of the improvement in Mrs. C.'s lymphedema management, we reduced the frequency of therapist sessions to every 3–4 weeks until 1 year. After she was discharged from the physiotherapy department, Mrs. C. had follow-up visits at the lymphedema clinic every 6–12 months, as per regular procedure.

The outcome measures described next were collected at follow-up visits.

Table 1 Lymphedema Self-Management Interventions Recommended to Mrs. C

Intervention	Description	Frequency
Compression therapy (self-applied)	Multilayer, short-stretch bandages, worn 24 h/d (reductive) or during nighttime (maintenance) Custom-made, flat-knit compression garment (arm sleeve and glove), worn during daytime (maintenance)	Daily
Exercise	Deep breathing or Casley-Smith remedial exercises ²⁰ General aerobic and resistance exercises	Daily ≥3–5 d/wk
Self-massage	Simple lymphatic drainage (Casley-Smith method ²⁰)	Daily (separately or with remedial exercises)
Skin care	Careful hygiene and application of low-pH moisturizer ¹ Regular inspection for cracks, wounds, or infections	Daily Daily
Self-measurement	Circumferential tape measurement (2–4 predetermined anatomic points on edematous limb)	Weekly (reductive) Monthly (maintenance)

Limb volume

The treating physiotherapist assessed circumferential tape measurements at specified distances in relation to anatomical landmarks¹⁸ on both upper limbs at each appointment. This method has shown to have high reliability and validity.²¹ Limb volumes were calculated using the truncated cone method. Percentage of excess volume (PEV) in the affected (lymphedematous) limb compared with the unaffected limb was calculated: $PEV = [(affected\ limb\ volume - unaffected\ limb\ volume) / unaffected\ limb\ volume] \times 100$. The unaffected limb was also remeasured at each visit to capture any fluctuations in volume that could be related to the effects of chemotherapy, weight changes, or other factors.

Exercise level

At clinic follow-up visits every 3–4 months, Mrs. C. reported on the type, frequency, duration, and intensity of deliberate leisure exercise she had performed in the previous week. Using the 2011 *Compendium of Physical Activities*²² as a guide, we calculated levels of leisure exercise in metabolic-equivalent task (MET) hours per week. A MET is estimated as the energy cost of a given activity divided by resting energy expenditure (1 MET = 3.5 mL/min/kg oxygen consumption).

MEASURES AND OUTCOMES

Adherence to modified complete decongestive therapy programme

Mrs. C. successfully learned self-bandaging, garment care, self-massage, and exercises by practising with the physiotherapist during her weekly appointments and by following written instructions and photographed or videotaped sessions at home. She also enrolled in an exercise programme at a community centre, where a trainer provided close supervision and communicated regularly with the treating physiotherapist.

During the reductive phase of the modified CDT programme (commencing in June 2012), Mrs. C. practised

self-bandaging every day (sometimes rebandaging to correct loosening compression). At home or the community centre, she also performed daily deep breathing, remedial²⁰ or general aerobic and resistance exercises, or self-massage.²⁰ Self-bandaging continued over several months to accommodate limb-volume fluctuations (potentially attributed to chemotherapy, steroid medication, and weight changes). When Mrs. C.'s medical status stabilized and her treatment changed to trastuzumab only, her limb measurements stabilized, and she obtained a custom-made compression garment for maintenance (December 2012). The garment consisted of an arm sleeve and a separate glove, both of compression class 1 (20–30 mmHg). About 1 year after she had begun the CDT programme, she was continuing daytime compression (garment and occasional self-bandaging) and daily exercise.

Limb volume and percentage of excess volume

When Mrs. C. first presented to our clinic (June 2012), her lymphedema was moderate in severity,¹⁹ with 26.8% excess volume in her left arm compared to her right arm (17.1% upper arm, 41.6% lower arm). She had a BMI of 31.2. Four weeks after initiating the modified CDT programme, Mrs. C.'s left upper-limb volume was reduced from 2,847 millilitres to 2,323 millilitres, and PEV was reduced to 5.9% (5.9% upper arm, 6.0% lower arm). Despite several fluctuations in limb volume, PEV was stable overall at 3.0% (–0.9% upper arm, 8.8% lower arm) by June 2013 (see Figure 1). In September 2013, her BMI was 29.1.

Exercise level

In June 2012, Mrs. C. had been avoiding all functional activities requiring the use of her left upper limb as well as any deliberate leisure exercise (0 MET h/wk). In July 2012, she commenced a community-based exercise programme, described in Table 2. Exercise intensity, duration, and frequency were increased gradually, with a maximum of one new exercise introduced per session. Over several months, Mrs. C. augmented her exercise

Figure 1 Percentage of excess volume in Mrs. C.'s lymphedematous limb.

Table 2 Details of Exercise Programme Carried Out by Mrs. C.

Date	Frequency	Exercise programme
July 2012	3–4 × /wk	Casley-Smith remedial or deep-breathing exercises daily Tai chi or qigong, 1-h classes, 1–2 classes/wk Low- to moderate-intensity cardiovascular training on recumbent bike, 10–15 min/session, 2–3 sessions/wk Core and lower body resistance exercises, 2–3 sessions/wk
September 2012	4–5 × /wk	Tai chi or qigong, 1-h classes, 2 classes/wk Low- to moderate-intensity cardiovascular training on recumbent bike or walking, 15–30 min/session, 3–4 sessions/wk Core and lower body resistance exercises, 2–3 sessions/wk Upper body* resistance exercises (lateral and forward shoulder raises, long-arm triceps pull-down, short-range row pull), 2–3 sessions/wk
February 2013	6–7 × /wk	Tai chi, qigong, or yoga, 2 classes/wk Moderate-intensity interval cardiovascular training on recumbent bike, recumbent cross-trainer, or walking and jogging, 30–60 min/session, 4–5 sessions/wk Resistance exercises for upper body,† core, and lower body, 2–3 sessions/wk

*Exercises performed with left upper limb in compression bandage, with left elbow in neutral position and using low resistance (1–3 lb).

†Exercises performed with left upper limb in compression garment (arm sleeve and glove).

level (see Figure 2) and reported increased use of her left upper limb for daily activities, including cooking, bathing, and typing on the computer.

Four-year follow-up

In June 2016, more than 4 years after being diagnosed with lymphedema, Mrs. C. was continuing to receive

pharmacological treatment with trastuzumab. To control her lymphedema, she wore a compression class 2 (30–40 mmHg) arm sleeve and glove. Her lymphedema remained mild in severity, with an excess limb volume of 9.7% (0.4% upper arm, 21.5% lower arm). At this time, her BMI was 30.8. She continued daily exercise of

Figure 2 Leisure exercise levels in metabolic-equivalent task (MET) hours per week.

walking, dragon boat paddling, and weight training, reaching an average of 36 MET hours per week. On evaluation, she reported having improved physical function, noting increased walking tolerance and motivation. “Last month, we stayed two weeks in Europe. There, I was able to walk, on average, fifteen kilometres a day! That motivates me a lot, makes me think that I still can.”

She also stressed the value of lymphedema self-management strategies from a patient’s perspective.

Lymphedema is a chronic disease; educating the patient and his caregivers in self-management makes lymphedema treatment accessible to everybody ... Also, I think that the fact of knowing how to control it could improve the self-confidence and self-esteem of the patient.

IMPLICATIONS

Awareness of malignant lymphedema

Lymphedema is a debilitating consequence of cancer and its treatment, and it is associated with chronic swelling, increased risk of cellulitis, long-term functional issues, and poor quality of life.^{9,23,24} Malignant lymphedema, caused by direct tumour invasion or obstruction of the lymphatic vessels, has not been well explored in the literature. As demonstrated by Mrs. C.’s history, there may be a lack of awareness in the medical community of the appropriate and timely diagnosis and treatment of malignant lymphedema. With improving survival rates in advanced cancer, more people live with the complex, long-term issues caused by cancer, including lymphedema. Oncology health professionals need to be informed about the different causes and factors associated with lymphedema. Likewise, suitable treatment options

should be made available and accessible to individuals with this condition.

Self-management strategies for malignant lymphedema

Few studies have explored self-management interventions in the population with lymphedema, particularly in cases of malignant lymphedema, in which management may be complex and intensive over a lengthy period. Self-management strategies are important because they empower patients with the knowledge and tools to adequately manage their lymphedema.¹⁸ Moreover, given the potential health care demands of CDT, such approaches can potentially improve patients’ adherence to and success with treatment. In a study of patients with breast cancer-related lymphedema, the self-care modalities recommended by clinicians were generally consistent with current guidelines; however, the prescription rates of these strategies tended to decrease over time.²⁵ In addition, sub-optimal adherence by patients to these modalities was reported in this analysis.

In this article, we present a unique case report of Mrs. C., a motivated woman with malignant upper limb lymphedema caused by advanced breast cancer who successfully adopted and tailored self-management strategies. Over time, she benefited from improved limb volume, leisure exercise levels, and self-reported physical function. This is particularly important in cases of malignant lymphedema, in which it may not always be possible to stabilize fluctuations in volume because of changing tumour responses and effects of treatment. Self-management strategies may instead offer patients accessible treatment options to manage the symptoms associated with their lymphedema, maximize their physical function, and improve their feelings of confidence and self-esteem.

Considering the pathophysiology of malignant lymphedema caused by tumour compression of the axillary lymph nodes, it can be argued that chemotherapy may have contributed to the positive changes in Mrs. C.'s outcomes. In fact, the long-term control of lymphedema can likely be attributed to effective anti-cancer treatment. However, the findings of immediate short-term improvement in Mrs. C.'s edema after a 3-month history of increasing limb volume despite receiving chemotherapy are likely a result of initiating CDT. Also, given the chronic fluid accumulation and fibrosclerotic changes associated with lymphatic stress and the irreversibility of lymphedema, lifelong management with compression therapy is usually necessary for patients with malignant lymphedema. Thus, this case report highlights the potential value of self-management options for successfully controlling this condition.

It is important to note that some patients with lymphedema may not have the capacity to learn and fully implement these strategies because of physical restrictions (e.g., joint stiffness from arthritis), symptoms (e.g., fatigue), psychological issues (e.g., severe anxiety), or cognitive limitations (e.g., inability to read and follow instructions). In particular, patients with advanced or metastatic cancer with concerns such as muscle weakness, pain, and loss of energy may not be able to adequately perform certain self-management techniques. In such cases, the role of caregivers, family members, and community health care providers in supporting these patients becomes increasingly important.

In our clinical experience, and as this case report demonstrates, most patients and their caregivers can benefit from some level of guidance on self-management strategies to control lymphedema. Such education can be a valuable addition to patient-centred practice. Self-management techniques should be tailored and adapted to a patient's status, including medical status, symptoms and physical capacity, and access to social support and financial resources. Further studies exploring treatment strategies, particularly in complex types of lymphedema, are needed.

Effective self-management of lymphedema

The successful implementation of self-management strategies for lymphedema depends on several factors. Research has reported that barriers to the optimal self-management of lymphedema were related to physical capacity (difficulty with bandaging, modifying clothing), time, discomfort, financial costs, and motivation.^{26,27} Patient knowledge has been identified as an important factor in adherence to self-care strategies for individuals with breast cancer-related lymphedema.²⁸ Educating patients soon after diagnosis about the development and progression of lymphedema, available treatments, and their role in managing the condition may be beneficial. Among affected individuals and their caregivers, motivation and a willingness to learn, as well as actually

practising the different methods of self-management, may also enhance the successful long-term control of lymphedema. Patients may benefit from frequent opportunities to connect with lymphedema-trained specialists for problem solving and feedback, particularly when treatment is initiated. This is best done through in-person follow-up visits, but alternative options can include the use of videoconferencing or other communication technology tools.

Appropriate patient education may involve giving verbal instructions and using combined multidimensional, and sometimes creative, approaches, including non-verbal methods such as diagrams, written instructions, photographs, and videos.²⁹ Demonstration and hands-on practice sessions may be particularly useful to ensure that patients and caregivers are comfortable with the different techniques. Effective performance of certain self-management techniques, particularly applying compression bandages and donning garments, often require manual dexterity, strength, and flexibility. Thus, caregivers can also play an important role in facilitating self-management.²⁹

It is important that oncology health professionals, lymphedema-trained clinicians, patients, and caregivers be informed about the different treatment components and options to appropriately manage lymphedema. Clinicians, particularly those trained in lymphedema therapy, would benefit from opportunities to acquire the skills and resources to adequately educate patients in self-management practices. Regular, effective communication among health professional colleagues about lymphedema assessment, treatment methods and associated precautions, and coordination of clinical interventions would be helpful to enable a holistic approach to lymphedema care, particularly in complex cases requiring long-term management.

Finally, financial support and additional resources, such as professional support in exercise training, may be especially beneficial for patients during CDT. Patient safety and lymphedema-related precautions related to exercise are important to consider. Specialized interventions that are accessible by and cost effective for the population with lymphedema need to be further explored.

Long-term lymphedema management

Given the chronic, irreversible nature of lymphedema, its long-term management requires careful consideration. The CDT strategies necessary to maintain stable limb volumes can be particularly challenging for patients to observe over time. In our report, despite Mrs. C.'s adherence to compression therapy and exercise, she demonstrated an increase in her lower arm volume from her 1-year visit to her 4-year visit and similar changes in her BMI. In general, several factors may influence the progression of lymphedema, including disease and treatment status, nutritional status and body weight, activity

levels, compression tolerance, and other potential triggers (trauma, injury, cellulitis infection).¹⁹ Also, it is important to note the challenges of assessing lymphedema using circumferential measures, such as difficulty with capturing hand volumes. Nonetheless, the long-term management of lymphedema has been documented as a challenge for this population,³⁰ and it is an area requiring further investigation. Follow-up therapist visits, nutritional counselling, and community-based programmes such as exercise classes, educational workshops, and support groups may be useful strategies for helping patients manage their lymphedema over time.

KEY MESSAGES

What is already known on this topic

Although traditional decongestive therapy has been found to be effective in the treatment of lymphedema, the successful, long-term management of this condition may be costly and time consuming for affected individuals. Little is currently known about self-management strategies for lymphedema, particularly malignant lymphedema.

What this study adds

In this case report, a guided self-management lymphedema treatment programme, including self-bandaging and exercise, successfully reduced swelling and improved exercise levels for a woman with moderate malignant lymphedema of the upper limb caused by advanced breast cancer. Educating patients about self-management strategies can play a valuable role in lymphedema therapy practice. Research is needed to further explore these interventions for patients with lymphedema.

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