Managing Lymphedema in Palliative Care

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Introduction

When serious and life-limiting illness hits, therapists, patients and family members alike wonder if it is possible or advisable to treat lymphedema. Even in the presence of advanced cancer and in palliative care settings, lymphedema can continue to be managed with decongestive therapies. However, there are special considerations under these circumstances. Aims of care may need to be shifted and the therapist may need to modify the decongestive techniques used. Family members have much to contribute to help improve the quality of life of their loved ones in these situations. Research is scant in this area, and much of the advice available is based on expert opinion only (ALFP Systematic Review 2012, ILF 2010).

The difference between benign and malignant lymphedema

Benign and malignant lymphedema are managed differently, so it is important to understand the difference between the two. Malignant lymphedema is due to active malignant tumour growth in the area that is swollen, whereas in benign lymphedema there may be damage to the lymphatic system related to oncologic treatments, but there is no cancer affecting that particular part of the body at this time (Weissleder and Schuchhardt, 2008). In this context, the medical term “benign” does not imply that the lymphedema condition is unimportant.

In patients with metastatic cancer, the therapist will require information from the referring physician about whether the lymphedema is due to active cancer in that site, or whether it is related to a non-malignant cause. Treatment approaches and expected outcomes can be very different. For example, a patient with longstanding breast cancer-related lymphedema and newly diagnosed brain or bone metastases has tumours in locations that may not impact the affected lymphedematous limb: In this case, the lymphedema continues to be benign, and decongestive treatment modalities may not make a significant impact. The patient can often continue with management strategies as before, provided that pain, fatigue or other symptoms do not interfere. However, to continue with the same example, if the patient should develop metastases in the chest wall on the affected side or in the axilla, then the lymphedema would be termed malignant, and special treatment approaches are required as outlined below. In summary, the only way to know if lymphedema is benign or malignant and to make an appropriate and reasoned treatment plan is to ask the treating physician and perhaps obtain copies of scans that outline where the tumours are. In any case, the therapist will need to be working closely with the physician when treating these often very ill patients.

Malignant lymphedema can appear or get worse suddenly and can be associated with abnormal venous patterns and other changes (see table 1).

Some common co-existing conditions that can produce edema in advanced cancer

In advanced cancer, lymphedema is often complicated by other causes of swelling. It is crucial to have a proper medical diagnosis of the many possible causes of edema. These other etiologies (Table 2) may make the lymphedema more of a challenge to treat with compression. Low albumin, as seen with the anorexia-cachexia of advanced cancer, and immobility are the most common challenges. In the presence of lymphedema it is worthwhile to attempt compression treatments even in these mixed cases, unless the physician signals that pain, fatigue or other symptoms do not interfere. However, to continue with the same example, if the patient should develop metastases in the chest wall on the affected side or in the axilla, then the lymphedema would be termed malignant, and special treatment approaches are required as outlined below. In summary, the only way to know if lymphedema is benign or malignant and to make an appropriate and reasoned treatment plan is to ask the treating physician and perhaps obtain copies of scans that outline where the tumours are. In any case, the therapist will need to be working closely with the physician when treating these often very ill patients.

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Table 1: Distinguishing features of benign versus malignant lymphedema

<table>
<thead>
<tr>
<th>Benign lymphedema</th>
<th>Malignant lymphedema</th>
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</thead>
<tbody>
<tr>
<td>Can develop more slowly (over months, years)</td>
<td>May have shiny skin due to rapid onset (weeks)</td>
</tr>
<tr>
<td>Mostly painless</td>
<td>Marked pain (requires analgesics)</td>
</tr>
<tr>
<td>Varices possible</td>
<td>Collateral veins and cyanosis are frequent</td>
</tr>
<tr>
<td>Tissue consistency: soft, fibrotic, sclerotic</td>
<td>Firm or wax-like tissue consistency</td>
</tr>
<tr>
<td>May have longstanding nerve damage due to</td>
<td>New onset paresis: nerve damage due to tumor infiltration</td>
</tr>
<tr>
<td>radiotherapy</td>
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</table>
Table 2: Some possible causes of edema in advanced cancer

<table>
<thead>
<tr>
<th>Cause</th>
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<tbody>
<tr>
<td>Tumor involvement or infiltration of lymph nodes or vessels</td>
</tr>
<tr>
<td>Venous obstruction (thrombosis, external compression by tumor)</td>
</tr>
<tr>
<td>Hypoalbuminemia (anorexia/cachexia syndrome, ascites and repeated paracentesis)</td>
</tr>
<tr>
<td>Kidney, liver or heart failure</td>
</tr>
<tr>
<td>Dependent limb, neurological deficit, immobility</td>
</tr>
<tr>
<td>Side-effects of drugs or cytotoxic chemotherapy, e.g. docetaxel</td>
</tr>
<tr>
<td>Cellulitis</td>
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that there is a co-existing medical contraindication.

**Special cautions**

If the patient is short of breath, especially if it is acute, medical advice needs to be sought regarding the cause. Standard contraindications for compression treatments apply in palliative care. Examples include acute deep venous thrombosis (which often occurs in advanced cancer), severe arterial insufficiency and uncontrolled congestive heart failure. Because these conditions are more common in those with advanced illness, close collaboration with the medical team is paramount. However, in palliative practice, contraindications can be relative rather than absolute. Bone fragility may be present in patients with bone metastases (especially breast, lung and prostate cancer). This may limit exercise interventions.

**Psychosocial factors that can impact treatment of lymphedema in the palliative setting**

Dealing with advanced cancer poses an emotional, psychosocial and existential challenge for patient, family and health caregivers. As a rule, family members wish to do everything possible to ensure the comfort of their loved one, but their time (and possibly, finances) may be taken up with palliative oncologic treatments as a desperate attempt to prolong life. Their lives have suddenly become a roller-coaster, and the challenge is for all concerned to constantly reframe the meaning of hope. Lymphedema therapists who may have known the patients for years beforehand also become involved in this dynamic. One of the dictums of palliative care is to never abandon your patient. The therapist will have to face his or her own emotional reactions. Although it is difficult for health caregivers to follow through under these difficult circumstances, they must try to do so using the psychosocial support resources of palliative care programs where these are available. Therapist self-care becomes important (mentioned later). Contrary to what we might have learned in our professional training, relaxing one’s “stiff upper lip” and sharing our grief becomes acceptable.

**Role of the family**

Normally, outside the palliative care context, we ask patients to take responsibility for their lymphedema management. However, the approach is different in the presence of advanced illness. The therapist should make use of family resources as much as possible. For example, a spouse might help with self-bandaging and simple lymphatic drainage. However, this needs to be done in a flexible fashion because family members are often exhausted. We want to protect the patient by devolving responsibility for care onto the family, but we need to be aware that families are under stress as well. In the best case scenario, community resources will be available to help (relatives, friends, church groups, community nurses, physiotherapists, occupational therapists, volunteers etc).

**The importance of continuing oncologic treatment**

The patient and family need to understand that the best treatment for malignant lymphedema, even in the palliative setting, may be to continue oncologic treatment (palliative chemotherapy, radiotherapy etc.) Sometimes patients will hesitate to follow the oncologist’s advice regarding these cancer treatments. For example, they may argue that radiotherapy in the past might have caused their lymphedema in the first place, so why should they have radiotherapy now? Won’t that make the lymphedema worse? However, if there is a recurrent tumor or metastatic disease in that watershed area, oncologic treatment is often the most effective treatment for the lymphedema, with compression being an adjunct. Although we may be only “buying time,” specific antitumour therapy can lead to better pain and lymphedema control and improved quality of life.

**Redefining aims of lymphedema care and outcome measures**

Goals and treatment plans are important in the palliative context, as in any therapy situation. Goals of treatment, however, may need to be modified. For example, the goal may be to improve function and symptoms rather than reduce edema volume. One may wish the person to remain independent for as long as possible, or enhance their sense of control. Or, one may wish to prevent or control oozing (lymphorrhea). Once the therapist determines which expectation is realistic, this needs to be communicated to the patient and family. A goal that is always present is to maintain human touch, connection and personal care.

**Different approaches to treat malignant lymphedema: how to adapt decongestive therapies** (Towers et al 2010, 2012)

In palliative care there is less distinction between the phases of lymphedema treatment. Where does reduction treatment end and the maintenance phase begin? Often they are one and the same, with bandaging being the key element.

“Gentle and slow” and “Do no harm” are the guiding principles. Flexibility is another. Before bandaging, the therapist needs to be aware that the tumor may be compromising the arterial circulation in the limb. Sensation may also be reduced, or pain may be present. Malnutrition may lead to tissues that break down more easily under pressure. The approach needs to be gentle and conservative. In adapting bandaging, one may need to reduce the pressure used, with fewer bandage layers. Close monitoring of any compression treatment is essential. The skin and tissues need to be checked frequently so bandages should not be left on for days at a time. If lymphorrhrea is present, bandages may need to be changed more than once daily to deal with oozing. Soft padding may be better tolerated than more rigid products. Once the edema is improved, one may need to continue with 24 hour bandaging to control it, since garments are poorly tolerated in the palliative setting.

Severe fatigue is a common complaint in advanced cancer. Techniques and
treatment times need to be modified accordingly.

Dealing with specific challenges: pain, lymphorrhea, malignant wounds, truncal and genital edema

Modern palliative care has become very efficient in controlling cancer pain in almost all cases. Co-existent pain will need to be carefully managed by the palliative care team so that lymphedema treatments can proceed. Undertreated pain should never be accepted as “inevitable.” Be aware that there may be a risk of pathological fractures with bone metastases.

Lymphorrhea (fluid oozing through the skin) can usually be prevented or controlled with early use of standard bandaging techniques. With the consent of the treating physician, one can bandage over malignant wounds if this is tolerated by the patient.

Truncal and genital edema can be addressed with manual lymph drainage, specific simple lymphatic drainage with the help of family members and special adhesive taping techniques.

Use of garments and special compressive devices

Palliative care patients do not tolerate elastic compression garments well, either due to the high resting pressures or because there is marked limb deformity. But the most important factor that renders garments less useful is that malignant lymphedema is often variable: one day the edema is good, and the next day it is bad. Therefore, it is a challenge to try to find garments that fit, even if they are custom made. The distorted limb shape can also lead to a tourniquet effect. Garments that have adjustable Velcro bands can be useful both for day and night wear. Special commercial or therapist-fashioned foam sleeves over which the patient or family can self-bandage are also useful.

Limitations of pneumatic compression devices

In palliative situations, pneumatic compression devices have limited usefulness because of the tendency to develop proximal, genital or truncal edema. Research is required on the use of pumps that have truncal sleeves in the palliative setting.

Diuretics and other medication

Although diuretics are generally not indicated in benign lymphedema, in the palliative context, the physician may choose to try diuretics, which may need to be administered in high doses to have an impact. Physicians will sometimes try dexamethasone to try to reduce peritumor edema and distal swelling. However, long term use of steroids can itself cause edema.

Subcutaneous controlled drainage, or reverse clysis

When edema is massive and survival time is limited, other palliative approaches have been tested. An old technique of interstitial fluid drainage using large-bore needles has been refined and described in case series reports (Clein and Pugachev, 2004, Bar-Sela 2010). This method is used only if standard CDT has failed or is felt to be futile. One subcutaneous drainage technique involves inserting size 19 butterfly-type needles into the subcutaneous space and connecting them via tubing to a dependent drainage container, such as a biliary drain bag (Clein, 2009). Bandages can be applied once the needles are inserted. One theoretical concern about this technique is the risk of introducing infection. In Clein’s case series, no patients developed infection, but their median survival time was only two weeks. Centers that use this technique are encouraged to publish their case series, as there are few reports in the existing literature.

Self-care for the therapist

Attention to the caregiver’s own emotional state is an important part of the philosophy of palliative care. The philosophy of non-abandonment of the patient has great implications for the therapist in terms of having to be flexible, organizing one’s time and dealing with one’s own emotional stress. Therapists often form close bonds with palliative patients and their families. At times, therapists will have to acknowledge their reactions and emotions and allow time for grief and strong feelings. It may help to discuss the situation with other team members. Showing vulnerability is allowed. Peer support for health care providers is strongly encouraged and is essential in palliative care.

Areas for future research and development

We need more publications that highlight experience with palliative patients. It is difficult to do randomized trials in this population; however case series and cross-over trials would be helpful. Even case examples highlighting the creative use of compression materials would be welcome. The viewpoints of family members who have gone through this experience should be documented and published as well.

Conclusion

Lymphedema therapists are becoming increasingly integrated within palliative care teams. However, even if the therapist is a visitor to the team, frequent communication with the physicians, nurses and other team members will ensure a good outcome. Adapting standard compression therapies may improve the quality of life in those with advanced cancer and may help maintain function and prevent or improve lymphorrhea, heaviness and pain. Sometimes in palliative care, especially when there are irreversible co-existing medical conditions, lymphedema treatment results are less than adequate, despite everyone’s best efforts. Even in such cases, it may be a great comfort for the patient and family to know that one is trying one’s best (Cheville, 2002) and that we are not abandoning the patient.

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