

Evidence and tradition in conflict: The Swedish experience of lymphoedema treatment and care

Polymnia Nikolaidis, Katarina Karlsson

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Polymnia Nikolaidis and Katarina Karlsson, Physiotherapists and Lymphoedema Therapists, Department of Cancer Rehabilitation, Karolinska University Hospital, Stockholm, Sweden

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The treatment of chronic oedema and lymphoedema varies around the world. The availability of treatment varies and is determined by the patient's distance from the therapist and the number of trained lymphoedema therapists at a given facility. Cost is a further barrier to receiving optimal treatment.

Clinicians in different countries often choose different treatments and strategies. At the recent International Society of Lymphology congresses in Rome and Malmö (16–20 September 2013 and 19–23 September 2011, respectively) the variations were evident.

Global variations

In parts of the world where filariasis is the common cause of secondary lymphoedema (e.g. India, Thailand, and other parts of Asia, as well as South America), patients do not present until their condition is significant in terms of swelling. Health care is reactive and the focus is more on functional issues.

Generally, the main goals of treatment are to increase the individual's mobility, promote return to work (where applicable), and restore the person's ability to support themselves. Of course, there is also the need to better control of the vectors (i.e. mosquitoes in the case of filariasis) to achieve prevention.

Abstract

The basis of Swedish lymphoedema treatment programmes were first developed in Germany early last century. The treatment principles remained the same until recent years and are based on manual lymph drainage, compression, skin care, and exercise. However, our experience is that it is important to assess patients holistically and therefore other approaches to treatment may be better. We suggest that less emphasis be placed on manual lymph drainage and more on compression, exercise, and weight reduction.

In a developed country like Sweden, patients generally present early, the oedema volume is usually low, and oedema is mainly related to cancer treatment. Knowledge of cancer-related oedemas is important. These are often recognised at an early stage and the lymphoedema treatment is an integrated part of rehabilitation.

However, access to care may vary, particularly due to geography and clinician availability. The goal of lymphoedema treatment is not only to reduce and/or improve function, but also to improve patients' quality of life and – for those at risk of developing lymphoedema – deliver education on prevention.

Swedish lymphoedema care

Stockholm, with a population of around 1.5 million, currently has 53 registered lymphoedema therapists in primary care, and 17 in home and palliative care teams. There are also a couple of private rehabilitation clinics out of which 12 therapists operate. This means that there is one therapist per 18 750 inhabitants.

In Sweden, a doctor's referral is not required for a consultation with a lymphoedema therapist and patients often contact lymphoedema therapists in primary care directly.

Lymphoedema therapists are generally fully responsible for initiating and evaluating the lymphoedema treatment plan. This includes the ordering and fitting of compression garments and stockings. This is an advantage as the therapist follows the person from diagnosis to endpoint and can continue to monitor, manage, and evaluate the patient.

Follow-up visits with patients after lymph node surgery are routine. This includes patients with malignant melanoma. Patients are provided with preventive information early (usually the day after surgery) and are normally followed-up 4–5 weeks later by a physiotherapist/lymphoedema therapist, either individually or in a group.

At the follow-up visit, an assessment of joint mobility is conducted and the patient is informed about the basic functioning of the lymphatic system, skin care, and the importance of performing some kind of physical activity. These individuals are encouraged to begin their physical activities as soon as possible, preferably 2–3 weeks postsurgery.

People who were previously physically inactive are advised to take up some kind of exercise for the upper body – such as swimming, pole walking (Nordic walking), weight lifting, cross country

skiing, or rowing – in order to stimulate the lymphatic and blood circulation. In the case of inguinal clearance, cycling and swimming are recommended. At this visit the therapist will measure the limb and order compression stockings or sleeves, in case oedema should develop.

There are many benefits of early diagnosis and treatment (Ramos et al, 1999; Johansson and Branje, 2010). Patients can either eliminate minor oedema or reduce it to a level that does not affect their activities.

In terms of rehabilitation, at Karolinska University Hospital in Stockholm, patients are educated to recognise the early signs of lymphoedema and usually present early with minimal oedema (stage 0–2).

For breast cancer patients, compression garments or bandaging are recommended for a few days in most cases to reduce oedema, if needed, and thereafter measure and fit a compression garment.

Manual lymph drainage (MLD) performed by the lymphoedema therapist is never the first choice of treatment. Patients are informed about the lack of evidence for MLD, but are encouraged to undertake self massage for a short period to evaluate its effects. Where self massage is ineffectual, the patient can discontinue and focus on wearing compression garments and being physically active. Patients are encouraged to begin some form of exercise for improving circulation (Schmitz et al, 2010; Kwan et al, 2011).

In cases of advanced cancer, the treatment plan is different and depends on factors such as venous obstruction, medication-related oedema, levels of plasma protein, activity, oncological treatment, and oedema status. Treatment is mainly aimed at improving function and comfort.

Treatment expectations

Patients may have different goals, motivations, and expectations of treatment. For a patient with high levels of oedema, a reduction in oedema may mean that they can return to work, for another, even a small volume of oedema may negatively impact self confidence and self esteem with the accompanying psycho-social consequences. Thus, patient expectations may not always coincide with the lymphoedema therapist's goals and expectations of treatment.

A shift in care

Traditionally, the main outcome measure of successful lymphoedema treatment has been reduced oedema volume. Treatment has been focused on MLD. However, based on more recent research, a paradigm shift in therapy is underway. In the future, therapists will most likely emphasise holistic care, favouring compression therapy and physical activity over MLD.

In recent years, there has been contradictory evidence of the value of MLD. Research is not always convincing, and MLD has not proven to reduce the volume of lymphoedema (Kärki et al, 2009; Huang et al, 2013).

Physical activity in cancer care is important because it has been shown to reduce the side effects of treatment (e.g. pain, fatigue, and nausea) and improve quality of life, physical strength, and mobility (McNeely et al, 2006).

Lymphoedema therapists need to examine how we can accelerate change in our approach to oedema management and how this should be integrated into health care systems.

Patient responsibility

The level of responsibility the patient is expected to take is different around the world. In some countries, the patient is passive – they expect the therapist to take full responsibility for their oedema treatment and they willingly place themselves in the hands of the therapists. In other countries, emphasis is given to the patient accepting responsibility for their treatment and the therapist has a more guiding role.

A good clinical outcome is more likely to be achieved if the therapist and patient agree on treatment goals and the patient's obligations (i.e. some form of contract exists). The therapist must be clear about what is required of the patient and encourage them to ask themselves: "What have I done for my oedema/limb today?"

It is also important to enhance and reinforce the patient's ability to cope with everyday oedema care, which may be tiresome for some people (Piller, 2012).

Some oedemas are complex and this is particularly true of lower-limb oedema. Few secondary lymphoedemas are solely of lymphatic origin and there is usually venous insufficiency present to some degree. This means that patients respond

differently to both compression and physical activity.

Often the lymphoedema therapist has to assess which therapies work best for the individual. At times, it can be a "try and see" approach, where one change is made at a time and its effect is measured.

Primary lymphoedema is relatively rare and commonly underdiagnosed, which contributes to the fact that this group of patients usually presents at a later stage than those with oedema related to breast cancer treatment. This late presentation makes the treatment more extensive and difficult and is compounded by the lack of doctors specialising in lymphoedema. This often means that a complicated patient is assessed solely by a lymphoedema therapist. Experience is critical in providing targeted and appropriate treatments to optimise outcomes. Fortunately, complex cases are becoming rarer, since knowledge about lymphoedema and its treatment are becoming more well known.

However, in Sweden, the authors know from experience that many newly trained lymphoedema therapists often do not have access to patients' medical records and do not have an experienced supervisor or mentor to ask for advice. This can compromise patient care and result in suboptimal treatment.

A further problem is that a physical therapist or lymphoedema therapist working in primary care will mainly treat other groups of patients, such as those with orthopedic, neurological, or muscle-related disorders. The therapist may actually assess, treat, and follow-up very few lymphoedema patients. It may take many years to gain clinical experience of the various types of oedemas and lymphoedemas, and of the optimal treatments. In an oncology setting, this does not pose such a problem as many patients are similar in terms of their treatment and present for therapy relatively early.

Education issues

Some lymphoedema therapist education programmes are short (sometimes only a few days in duration) and their targets are primarily cosmetologists and beauticians. In Sweden, longer courses (4–6 weeks) are only open to clinicians such as physiotherapists, nurses, and occupational therapists.

Nonetheless, the therapist in the shorter education programmes will often receive a certificate stating that they have received some degree of lymph therapist education. In Sweden, holding this type of certificate can mean a clinician is allowed to treat patients with secondary lymphoedema. Often this leads to people treating patients without possessing any basic knowledge of oncology or pathophysiology. Ideally, no person without a basic clinical qualification should be accepted for a lymphoedema therapy training programme.

The title “lymphoedema therapist” is not one of the professions covered by the Patient Safety Act in Sweden. This means that while lymphoedema therapists with no medical qualifications are not allowed to work and treat patients within the public healthcare system, they can still treat lymphoedema patients at private clinics. This must be borne in mind to ensure the limitations of knowledge and practice can be addressed.

As previously mentioned, therapists’ backgrounds vary and so does their therapeutic focus. For example, in England, nurses initially treat lymphoedema patients, and their main focus is on the skin and skin-related issues. While in Sweden, for the most part, physiotherapists treat lymphoedema. Therefore, the body’s musculoskeletal system and function and activity limitations are focused on. Fewer skin problems are also encountered by clinicians since patients are treated earlier in the process.

Self-care is key

The significance placed on physical activity in the treatment of lymphoedema in Sweden means that a large proportion of patients are required not only to take care of their skin and compression therapy, but also to exercise regularly. Thus, patients spend a lot of time managing their oedema treatment.

The lymphoedema therapist’s role in treatment is to guide, motivate, and empower patients, helping them take an active role in treating their oedema.

From clinical experience, the authors note that many patients choose to end their contact with the lymphoedema therapist. The reasons may vary, and we know from experience that some early oedemas decrease with time or disappear

completely and so the patient no longer needs or seeks any input from the lymphoedema therapist.

Some patients who have low volume oedemas request regular MLD. Those who live in the Stockholm area are able to receive such treatment from the many lymphoedema therapists in the city. Unfortunately, the wide availability of lymphoedema therapists may mean that some patients are over-treated with MLD, use compression when they do not actually need it, or become dependant on the lymphoedema therapist rather than independent.

Patients are sometimes frustrated when they cannot receive MLD in the way they did earlier in their treatment, or from what they know other similar patients have received. People also want other complementary techniques, such as laser therapy, compression pumps, and other methods they have heard about. Therefore, some patients are sometimes disappointed that the healthcare system is too evidence-based and does not use complementary methods to the extent they would like.

This leaves a number of important questions unanswered. Is it outcomes other than reduced oedema volume that some patients expect from treatment? How well can lymphoedema therapists meet these patients’ needs? Is the patient asking for MLD for reasons other than oedema/volume reduction? Is it perhaps the touch/tactile stimulation or the soothing effect of the MLD? Should this additional demand be met by lymphoedema therapists, or should these patients seek a private massage therapist?

A new approach to care

We need to consider if therapists need to be more holistic in their approach and integrate and accept other professions into the management of the patient. For instance, in some circumstances, could cognitive behavioural therapy help the patient better handle cancer, the impacts of its treatment, and the symptoms of the lymphoedema? Perhaps body awareness training, mindfulness, or yoga might help?

Patients frequently seek out patient organisations to meet other people in the same situation, gain knowledge from other patients’ experiences, actively questioning treatments, share their

collective knowledge of oedema, and often, importantly, what others think of available therapists. An important part of the work of these organisations is, therefore, to provide objective and evidence-based information to their members as well as convey to them the fact that not every method is appropriate in every case.

The research into lymphoedema treatment is limited. Not every therapy has a high level of evidence and there will often be contradictory reports. Presenting and acknowledging the balance is critical in ensuring therapists, patients, and patient organisations work together for the best outcomes. Communication is a critical part of this process. The interaction between the lymphoedema therapist and these organisations needs examining.

Conclusion

Lymphoedema treatment in Sweden is not perfect, but there is a great opportunity to make it better. A paradigm shift in treatment can more easily be implemented by greater holistic thinking and working in close cooperation with patient organisations.

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