

Lympho-logical thinking in self-management of lymphoedema



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The Kaiser Permanente triangle suggests that up to 80% of all people with long-term conditions can control their disease using supported self care. The main aim of this investigation was to clarify the core components required for learning effective self care for patients with lymphoedema. A retrospective analysis of patient surveys and interviews over a 10-year period were analysed in order to answer key questions and ascertain how to provide patients with a solid knowledge base for self-management. The results show that the ability to monitor and act on an increasing change in limb volume is critical, and that teamwork between the patient and healthcare professional is essential until the patient has developed the skills needed to become an effective care manager.

Patient-centred care is a common topic on the international healthcare agenda. Partnerships between stakeholders are currently investigated with the aim of being to reduce costs for the healthcare system. Open-mindedness, transparency and collaboration between clinicians and patients have all been shown to improve the healthcare system^[1]. The competence and experience of both the healthcare professional and patient should be used to strive for an optimal management method and optimal outcomes for lymphoedema.

What is behind the concepts self care and self-management?

The Kaiser Permanente triangle — a healthcare model for chronic conditions that relates condition severity to level of intervention required — indicates that up to 80% of all people with long-term conditions, such as lymphoedema, could be managed using supported self-care^[2]. Consequently, it is very important how the knowledge of self care is presented and taught to the patient^[3]. The authors set out to address the following key questions in relation to lymphoedema self-management: ‘what makes a difference?’ and ‘what does it take to learn and teach?’

Four steps of learning

Experience has shown that for patients to develop into a ‘care manager’, they need to

understand that learning takes time, and both clinician and patient must acknowledge and accept where their baseline learning level is at. Burch^[4] proposed four steps to learning, ranging from unconscious incompetence to conscious competence. Relating to the competence of lymphoedema self care, the following steps are relevant:

- Unconscious incompetence — no knowledge of the existence of lymphoedema management
- Conscious incompetence — knowledge of the fact that lymphoedema can be managed
- Conscious competence — knowledge of how to manage lymphoedema
- Unconscious competence — managing lymphoedema unknowingly.

Main areas of knowledge

It is the lymphoedema therapist’s responsibility to enable the patient to become a ‘care manager’ for his/her condition. Evidence has shown that ‘usual care’ involving only healthcare professionals is not effective for the management of chronic conditions^[5]. The healthcare professional should not focus on symptom control, but instead act as a coach, while the patient takes on ownership of the problem^[5]. With this concept in mind, the authors used results from data obtained through surveys and interviews with patients to map the areas of knowledge that are required to reach the goal of self-care in lymphoedema.

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These surveys and interviews were undertaken via interviews for a booklet published in 2011 (printed in both Swedish and English and titled 'At Risk of Developing Lymphoedema after Breast Cancer Treatment — What Can I Do For Myself?'), and two postal surveys conducted in 2005 and 2007 where participants explained their lymphoedema treatment, anonymously.

These are:

- Anatomy and physiology of the lymphatic system
- Deep breathing
- Self manual lymphatic drainage (SLD)
- Skin care
- Compression techniques
- Physical exercise
- Factors affecting the swelling
- Emotional issues.

Every patient has a unique lymphoedema experience, partly depending on the individual degree of deficiency of their lymphatic system, but also related to the capacity to open his/her mind to understand the learning and then turn this into practice^[6]. The authors have found that guidance focusing on the areas mentioned above — keeping the four steps of learning in mind — will facilitate patients in finding their own individual optimal self-management level^[7,8,9]

Anatomy and physiology

Analysis of the data showed patients, once taught a basic understanding of the anatomy and physiology of the lymphatic system^[10], and how the lymphatic system can be activated, were more eager to learn the rest of the concepts of self-management, which included deep breathing, SLD, skincare and compression techniques. To enhance understanding, metaphors like 'sewer system', 'plumbing problems' and 'one-way street' were considered useful to patients gaining a better understanding of the intricacies of self-care.

Deep breathing

The negative pressure inside the chest when breathing makes deep breathing one of the fundamental ways to activate the most proximal, and also the largest, lymphangions^[11]. Many people with lymphoedema are living with stress — especially if they have undergone cancer treatment, but also related to not being able to deal with a constantly swollen arm or leg^[12]. When made aware of how important

the expansion of the vessels within the chest is when dealing with lymphoedema and how stressful situations inhibit breathing, the patient can easier adapt to include deep breathing in their exercise regimen. The effect of deep breathing on the largest lymph vessels was more easily understood by patients through the use of the metaphor 'like sucking up water in a syringe'.

Self lymphatic drainage

The understanding that blood circulation is constantly feeding fluid into the tissues and that there has to be a balance between outflow and inflow every day was found to aid patients in adapting to the daily implementation of SLD to activate the lymph flow. Patients felt more eager to conduct SLD when being shown how activating proximal parts of the lymph system can be seen on the texture of the skin. Understanding the importance of a 'pressure phase and a relaxation phase' in the manual lymph drainage (MLD) technique and that part of the SLD massage can be done over clothing, made a positive difference for patients^[13,14]. Patients also stated that one or two initial MLD treatments provided by the therapist made them more aware of what pressures and techniques to use when undertaking SLD^[15].

Skin care

In terms of introducing the patient to skin care regimens, it was found that using the metaphor 'the skin serves as an armour and protects us from infections adding to the lymph load' made the importance of skin care more comprehensible to the patient^[16].

Compression techniques

Given the knowledge that neither clothing nor bandaging should cut off the lymph flow at any time during the day, the patients themselves could gain control and avoid such obstacles or effectively manage any increase in swelling throughout the day^[17]. Introducing a number of compression options to choose from (different kinds of bandaging and garments of all colours and brands, including garments that were not subsidised by the government/public health insurance system) made it easier for patients to accept that compression may become a permanent reality in their lives^[18]. An awareness of the impact of the compression garment on the body during the day was helpful for the patient in working out an optimal fitting of the garment^[19].

Physical exercise

By understanding how their muscle movements can be used to stimulate the lymph flow, patients were more willing to undertake daily physical exercises^[20,21]. Patients also became more inclined to make a personal choice of exercise regimen and stick to it when introduced to a number of different exercise and training options^[22,23].

Listen to your body

To become a good 'care manager' of lymphoedema, patients also benefited from the request to 'listen to your body and try to notice what makes your lymphoedema get worse/better'^[6]. When patients consciously asked themselves over a period of time what might have enhanced their swelling, they would notice that, after a while, they unconsciously undertook activities to activate their lymph flow. These activities included toe and foot movements during meetings, shoulder movements while talking on the phone, deep breathing while waiting for the bus, or other remedies that they had noticed had a decreasing effect on their swelling.

Emotional issues

Many of the patients, especially those suffering from a sudden onset of secondary lymphoedema, were also mourning their body, pre-lymphoedema^[24,25]. They were more inclined to accept their lymphoedema diagnosis when their condition was recognised by the therapist and they were able to talk about it. Patients mentioned that, post-diagnosis, they felt dependent. This manifested as a feeling of dependence on a therapist and also a dependence on donning and doffing garments on a daily basis, as well as performing special exercises. The authors found that the more independent the patient felt, the better quality of life was noted. When in optimal control of their lymphoedema management, patients felt free to pursue other activities, such as gardening, travelling or other interests that they may previously have been too afraid to do.

What does not work to facilitate the development of the patient into a 'care manager'?

Through surveys and interviews with patients, the Swedish Association of Chronic Oedema (formerly Svenska Ödemförbundet (SÖF) has realised that many methods do not work when healthcare professionals try to transfer the knowledge of self care of lymphoedema to the patient^[26]. The most frequently mentioned were:

- The lymph therapist hands out a film with

pictures of lymphoedema and asks the patient to see the film together with his/her family and then acts as advised in the film

- The therapist hands out pictures with arrows showing how to self-massage, without explaining and making sure that the patient understands what to do
- The compression garment is sent home to the patient, who has to figure out by him/herself how to fit it and if it fits properly. Many patients had an experience of more swelling of peripheral areas, such as hands and feet and, consequently, gave up and put their garment in a closet
- When the therapist is impatient and requests that the patient wears a compression garment although the compression hurts and makes the more distal parts of the body, such as the hands and feet, swell
- Compression does not always work as a sole remedy. Many patients tell how they have been following all recommendations, wearing the compression garment day and night and only when subjected to methods activating the lymphatic system they were experiencing a change was seen for the better.

What it takes to learn and teach

The goal for the patient is to regain control of his/her body as much as possible. The goal for the therapist is to aid the patient in regaining control of the body^[27]. This process has to be fuelled by motivation. Without appropriate knowledge, the patient will have a hard time understanding why it is essential to manage lymphoedema and will become less motivated to do something about it^[28].

To transfer knowledge from one person to another takes teamwork. Since every person with lymphoedema is unique, has a unique background and a unique body that reacts in a unique way to different remedies, it takes a great deal of patience from both parties to find the optional solution for each individual. Only the patient will know what is the best way to handle his/her lymphoedema when given different options by the therapist and a thorough understanding not only that it affects their lymphoedema, but also how it affects it.

The therapist has a lot to gain in listening to the patient and trying to find solutions that fit the individual. It is also vital for the therapist to become reassured that the patient really is ready to take full responsibility and become the 'care manager' by letting the patient him/herself discuss solutions and alternatives when a situation of additional swelling occurs^[29].

Discussion

The Kaiser Permanente triangle indicates that up to 80% of individuals with a chronic condition can manage their disease using supported self care. The important issue then is to bring about an effective way to transfer the knowledge and knowhow so that those potential 80% have full control over their lymphoedema and require minimum assistance from the lymphoedema therapist. For this group of patients with lymphoedema, there will always be an ongoing need to see a therapist to ensure the lymphoedema does not progress and to prescribe new compression when needed.

By finding and using an effective model to teach the patient to take as much control of their lymphoedema as possible, the lymphoedema therapist can devote more of his/her time to patients who have a more severe dysfunction of their lymph system.

The big challenge is how to turn knowledge into practice. It is key that the therapist knows what the patient does not understand. The lymph therapist needs to find ways to coach the patient step by step through the learning process, until the patient feels that he/she can control the lymphoedema as much as he or she is capable of, considering the severity of the dysfunction of their lymph system.

A number of patients in the authors' interviews found it humiliating not to be believed by healthcare professionals when they told them about experiencing MLD as a determinant factor that had made a vital difference in their search for help to stop the progress of lymphoedema^[30]. Many of them had tried compression as a sole remedy for years. Among the comments patients received were: "Of course it feels good to get a massage" or "There is no evidence for MLD". Depending on the severity of the lymphoedema, some patients were found more dependent on intermittent MLD treatment by a lymphoedema therapist in order for their lymphoedema not to progress, while others needed just SLD once they received the required coaching.

Patients expressed a desire to be given individual guidance and support from a therapist when learning the SLD technique. All lymphoedemas are unique, depending of the nature of the swelling, and the pressure and pathways must be modulated to fit the individual. This means that the SLD programme varies from patient to patient. Also, many patients assume that SLD should

be applied primarily on the swollen part of their body, which calls for the therapist to make sure that the patient adheres to being thorough in activating the proximal parts of the lymphatic system before moving on to distal parts^[15].

One obstacle that will make the patient less able to handle his/her lymphoedema by him or herself without the help of a therapist, is a more severe dysfunction of the lymphatic system as illustrated by the 20% in the upper part of the Kaiser Permanente triangle. Other reasons could be age or multiple diagnoses, (for example, rheumatism) that make patients less capable of donning and doffing their compression or undertaking SLD^[18]. Research has shown that there are also psychosocial factors behind reluctance to perform self care^[31,32] and that may have to be recognised and dealt with.

Conclusion

For the patient to play an active role as 'care manager', rather than being a 'passive care consumer', it is important to understand what is required for patients to become empowered in self-management. The authors found that to achieve the goal of turning knowledge into practice, teamwork between the therapist and the patient is key^[33].

To understand and apply self care, the patient needs:

- To accept the diagnosis lymphoedema
- Simple explanations to be used
- Coaching until sure of the 'knowhows'
- Feedback — the patient and therapist together analyse which actions have been beneficial for the patient and which ones have not.

To teach self care, the therapist needs:

- To use simple explanations
- To use metaphors, if needed
- Patience with the patient
- To listen to the patient's story
- A pedagogic approach
- To make sure that the patient can reason and act lympho-logically when a swelling occurs.

With the goal of the best possible independence for the patient and with the four steps of learning in mind, close teamwork that educates the patient, and a perceptiveness for each patient's individual needs will pay off. A better quality of life for the patient, extra time for the therapist to treat more severe cases and, ultimately, cost-effectiveness for the healthcare system. In short, lympho-logical thinking will be achieved.

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