Lympho-Logical Thinking in self-management of primary lymphoedema and other rare diseases involving lymphoedema

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Background

Many patients benefit from knowledge
Primary lymphoedema is a progressive diagnosis. 70-80% suffering from chronic conditions such as lymphoedema can control their disease with supported self care according to the Kaiser Permanente triangle model.

Aims

Understanding self care of lymphoedema
Answer to the important questions:
- How is self care taught?
- What is understood?
- How obtain adherence?

Methodology

Surveys and experiences from SÖF and 20 years of clinical experience of a lymph therapist.

Result

Works
Guidance through the 4 steps of learning in the areas of:
- Anatomy and physiology of the lymphatic system
- Deep breathing
- Self Manual Lymph Drainage (SLD)
- Skin care
- Compression techniques
- Physical exercise
- Factors affecting the swelling
- Emotional issues

Does not work
Hand out a film with repulsive pictures of lymphoedema
Hand out a picture with arrows how to massage
Compression garments, rubber gloves and instructions sent home by mail
Impatience and demanding therapists
Compression as sole remedy

References

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The 4 steps of learning – for lymphoedema patients
1. Unconscious incompetence – no knowledge of the existence of lymphoedema management
2. Conscious incompetence – knowledge of the fact that lymphoedema can be managed
3. Conscious competence – knowledge of how to manage lymphoedema
4. Unconscious competence – managing lymphoedema unconsciously

What it takes to learn and teach

Patient
Goal: To gain best possible control of the lymphoedema
What is needed: Motivation
How obtain motivation: Knowledge

Therapist
Goal: To assist the patient in gaining best possible control of the lymphoedema
What is needed: To motivate the patient
What motivates the patient? Knowledge

Conclusion

To understand and apply self care the patient needs:
- To accept the diagnosis lymphoedema
- Simple explanations
- Coaching until the patient is sure of the “know-hows”
- Feedback - experiencing a result

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 part of the story
- A pedagogic approach
- Make sure that the patient can reason and act Lympho-Logically when swelling occurs

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