

Self-management in lymphedema

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Introduction

Patients with lymphedema suffer from various degrees of severity of swelling, limited range of motion, pain, loss of muscle strength, fatigue and subsequently loss of quality of life. Related to these problems, activities and participations in daily living are limited, *e.g.* personal care, walking, housekeeping, sports as well as working.

In both primary and secondary lymphedema the approach of swelling is changing towards early diagnosis, new treatment protocols and a larger contribution of the patients in the treatment of their own disease. Self-management and self-efficacy are therapeutical modalities during the maintenance phase and the role of the therapists is in that stage more hands-off and coaching.

Chronic care management and International Classification of Functioning Disability and Health

As lymphedema is a chronic condition, after the initial treatment phase a maintenance phase is mandatory. Both phases have their specific requirements. In chronic diseases a more integrated scope on a patient is needed. These requirements are reflected in the World Health Organization's (WHO) International Classification of Functioning Disability and Health (ICF) model.

¹ The ICF, international classification of functioning, disability and health, is based on an integrated bio-psycho-social model that allows a standardized description of functioning and disability based on individual and contextual factors. Using the ICF, influences upon a patient's functioning in three domains: i) body functions and structures; ii) activities of living; iii) participation in activities related to personal and environmental factors.

The principle of the chronic care model (CCM)² is active patient participation in his or her treatment, patient empowerment and self-efficacy and a more *hands-off* approach by health professionals. Effective electronic

patient files, accessible by all workers, follow a uniform protocol to support the care process.

Self-management

Self-management is one of the main parts of the Chronic Care Model. According to the Nivel (Dutch Research Institute for the health care system), 80% of all chronic diseased patients should be able to perform some form of self-management. Only 20% of them need more professional treatment. Taking care of your own chronic disease has shown to be a realistic goal for the lymphedema patient in the Netherlands, but the question is: are patients with extreme measures able to do the same, or do they belong to the 20%?

Obesity is a growing concern worldwide. The main risk factors for the development of lymphedema or worsening of an existing lymphedema are obesity/weight gain and lack of exercise.³⁻⁵ In lymphedema we often have to deal with obesity.

Early diagnosis is important as well as looking at other underlying problems, which can be described and monitored following the ICF. Besides therapy and adequate compression, self-management has become an important part of the treatment regime. However to become self-managing, patients need to be aware of their own situation/diagnosis, need to be able to understand the information and learn the skills, necessary for their treatment. Finally they must be willing to explore their own possibilities and to handle lymphedema/lipedema and to take their life in their own hands. This forms a great challenge for the professionals.

Subjects in self-management are: i) awareness and knowledge of their own condition; ii) self monitoring, clinometrics (*e.g.* weight measuring, pitting test, mobility, pedometer); iii) self treatment: applying compression technologies, skincare, exercise; iv) self efficacy.

Conclusions

The role of the healthcare provider (HCP) changes, especially in the maintenance phase, toward a health coach, as far as possible for the individual patients. The HCP performs clinometrics in the patient, possesses skills to reach behavioural changes to simulate health in the patient and works in a more hands-off manner. The

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Dutch guideline on lymphedema is based on the principles of ICF, chronic care management and positive health. Self-management plays an important role in that approach of the diagnosis and treatment of lymphedema.⁶

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