

# The use of International Classification of Functioning, Disability and Health Core Sets in a patient with lymphoedema in the upper extremity

PB Viehoff, YF Heerkens, RJ Damstra and M van Zanten

## Key words

International Classification of Functioning, Disability and Health (ICF), ICF Core Sets, Lymphoedema, Patient-Reported Outcome Measures

## Abstract

Patient-reported outcome measures (PROMS) are becoming increasingly important in daily health care. The International Classification of Functioning, Disability and Health (ICF) Core Sets can be tools to support this development. This case report describes an intervention for a patient with lymphoedema after multiple erysipelas infections and the use of the ICF Core Sets for lymphoedema to monitor treatment progress. The patient's answers to the questions based on the ICF Core Set were in line with the results of the outcome measurements used and these demonstrate their practical use.

*PB Viehoff is Physical Therapy Scientist, Centre for Physical and Manual Therapy 't Gilde, Gorinchem, The Netherlands; YF Heerkens is Human Movement Scientist, Dutch Institute of Allied Health Care, Amersfoort, The Netherlands; RJ Damstra is Dermatologist, Dutch Expert Centre for Lympho-vascular Medicine, Nij Smellinghe Hospital, Drachten, The Netherlands; M. van Zanten is Senior Research Practitioner, Molecular and Clinical Sciences Research Institute, St George's University London, London, United Kingdom*

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**L**ymphoedema is a chronic condition that is characterised by abnormal accumulation of lymph fluid in the body, due to inadequate transport (Stanton et al, 2009). It is caused by damage to or in the absence of lymph vessels and/or excessive production of extracellular fluid. Lymphoedema can occur in the limbs, as well as in the midline (head, neck, abdomen and thorax). There are two types of lymphoedema: primary (congenital or later in life often caused by a genetic mistake) and secondary (Stanton et al, 2009). Secondary lymphoedema is caused by damage to, or overload of, the lymph vessels or lymph nodes; it can occur after an injury, surgery, radiotherapy, infection or obesity (Williams et al, 2005).

As lymphoedema remains a poorly registered condition, prevalence is often unclear. According to a systematic review by DiSipio et al (2013), 14.8–16.4% of patients with breast cancer can develop lymphoedema. Conservative treatment of lymphoedema encompasses two phases. In the initial phase, treatment is intensive (6–10 weeks) until the lymphoedema stabilises. Then, the maintenance phase starts with a decrease in frequency and greater attention to self-management (Damstra et al, 2013). Lymphoedema is a chronic health condition requiring maintenance care (Bogan et al, 2007). Patients with lymphoedema experience heaviness and tightness of the limbs and

have a high risk of infection. In combination with a loss of mobility, this can lead to reduced quality of life (Fu et al, 2008). Additionally, reduced mobility can lead to problems in personal care, occupation, domestic life and socialising (Swenson et al, 2009).

## The International Classification of Functioning, Disability and Health

The International Classification of Functioning, Disability and Health (ICF) (Stucki et al, 2007) is an international framework consisting of a scheme representing the biopsychosocial perspective of health, with functioning

**Table 1. The brief ICF Core Set for lymphoedema of the upper extremity.**

ICF code	Description
b1263	Psychic stability
b164	Higher-level cognitive functions
b1801	Body image
b280	Sensation of pain
b4550	General physical endurance
b4552	Fatigability
b710	Mobility of joint functions
b730	Muscle power functions
d230	Carrying out daily routine
d445	Hand and arm use
d5	Self-care
d570	Looking after one's health
d5701	Managing diet and fitness
d640	Doing housework
d770	Intimate relationships
d850	Remunerative employment
d920	Recreation and leisure
e1151	Assistive products and technology for personal use in daily living
e310	(Support of and relationships with) Immediate family
e320	(Support of and relationships with) Friends
e355	(Support of and relationships with) Healthcare professionals
s420	Structure of immune system
s730	Structure of upper extremity

as a central concept and a set of four classifications (body functions, body structures, activities and participation and environmental factors).

For every health condition, health-specific selections of ICF categories (ICF Core Sets) (Stucki et al, 2002) can be determined, which makes the ICF easily applicable in rehabilitation medicine (Stucki et al, 2002). ICF Core Sets include the correct terms and classes to describe the functioning of persons with specific health problems, which makes the formulation of treatment goals easier, more transparent and faster. In 2015, ICF Core Sets for lymphoedema were determined (Viehoff et al, 2015). There are two Core Sets for lymphoedema (brief and comprehensive), each divided into three regions of upper extremity, lower extremity and midline. The Brief Sets can be used during individual

treatment, and the comprehensive in multidisciplinary settings.

To date, the patient-centered approach with Patient Reported Outcome Measures (PROMS) is becoming increasingly important (Højgaard et al, 2017). ICF Core Sets are considered PROMS as they can be self-administered and scored by the patient. Therefore, the Core Sets provide the healthcare professional with a general overview of the patient's wellbeing and outcomes that can serve as a basis for shared decision-making with the patient. For the purpose of daily use by patients, the rather abstract descriptions of the ICF (*Table 1*) were translated in plain, interpretable language and phrased as questions (*Table 2*). Responses are indicated on a three-point rating scale (satisfied, neutral and dissatisfied) and accompanied by smiling faces.

In this case study, functioning during treatment of a lymphoedema patient with an increased burden of disease due to erysipelas was tested and monitored, with the brief Core Set for the upper extremity.

## Methods

The patient was a 58-year-old woman with a Body Mass Index of 26 and a history of breast cancer. She experienced several episodes of erysipelas (*Table 3*) and was diagnosed with stage II lymphoedema (ISL, 2016) (*Table 4*).

## Examination

The patient received physical therapy treatment at an outpatient clinic 2 weeks after her hospitalisation for erysipelas. The patient lives together with her husband and has two married daughters. She was unemployed, spending her days as a housewife.

## Integumentary system

The lymphoedema of the patient involved the upper and lower left arm; the hand was not involved. She was treated with compression bandages as an inpatient, but this was discontinued upon discharge. Although the lymphoedema was reduced, wearing her compression sleeve was reportedly too painful. The skin of the arm was smooth and dry with no signs of erythema or warmth and the lymphoedema was non-pitting. Pain on tactile pressure was still present.

## Outcome measurements

Initially, the patient completed the brief ICF Core Set for lymphoedema of the upper extremity. Most of the problems were associated with pain, volume of the arm, mobility, stamina and muscle power. Afterwards, the patient used the European Organization for Research and Treatment of Cancer debriefing questionnaire to report difficulty with the questions and wording, and whether the questions were confusing or upsetting (Aaronson, 1990); the patient did not encounter such problems.

Pain was measured using a 10-point numeric pain scale (NRS). The patient rated pain in her arm as 4 out of 10. NRS has demonstrated good reliability and validity (Farrar et al, 2001).

The volume of the arm was measured with circumferential measurements using a plastic tape measure every 4 cm (Kuhnke,

**Table 2. Answers on the brief ICF Core Set for the upper extremity before treatment (T0), after 10 weeks (T1) and at the end of the treatment period (T2).**

ICF code	Description	T0	T1	T2
b1263	Are you irritable, worried, erratic or moody because of the lymphoedema?	😊	😊	😊
b164	Do you have problems with decision-making, planning and carrying out plans and time management because of the lymphoedema?	😊	😊	😊
b1801	Does the lymphoedema have a negative effect on your satisfaction with your body image?	😊	😊	😊
b280	Do you have pain caused by the lymphoedema?	😡	😐	😊
b4550	Do you experience problems with your stamina?	😡	😐	😊
b4552	Do you experience fatigue?	😡	😐	😊
b710	Is the mobility of your joints good?	😡	😐	😊
b730	Do you have enough muscle power?	😡	😐	😊
d230	Do you experience problems with your daily routine because of the lymphoedema?	😐	😊	😊
d445	Do you have problems with the use of hand and arm because of the lymphoedema?	😡	😐	😊
d5	Do you have problems with self-care because of the lymphoedema?	😐	😊	😊
d570	Do you have problems to look after your health because of the lymphoedema?	😐	😊	😊
d5701	Do you have problems managing diet and fitness?	😐	😊	😊
d640	Do you experience problems doing housework because of the lymphoedema?	😐	😐	😊
d770	Do you have problems with intimate relationships because of the lymphoedema?	😊	😊	😊
d850	Do you experience problems with remunerative employment?	😐	😊	😊
d920	Do you have problems with recreational and leisure activities?	😐	😊	😊
e1151	Are compression stockings, bandages or other compression devices available for you and are you satisfied about them?	😊	😊	😊
e310	Do you experience support of your immediate family?	😊	😊	😊
e320	Do you experience support of your friends?	😊	😊	😊
e355	Do you experience support of healthcare professionals?	😊	😊	😊
s420	Are there any lymph vessels or nodes missing?	😡	😊	😊
s730	Has the shape of your upper arm, forearm and/or hand been changed because of the lymphoedema?	😡	😐	😐

1976). Circumferential measurement of girth is a simple and valid method of determining limb volume (Hidding et al, 2016). The same method was used to measure the unaffected arm. The difference in volume was 15.8% and 335.8 ml.

Goniometry was applied to measure the mobility of the arm, especially the flexion of the shoulder, as this is the most important movement in daily practice. The goniometer is a reliable examination tool to objectively measure range of motion (Muir et al, 2010). At baseline, the flexion of the left shoulder was 108°.

### Evaluation

Due to the erysipelas, the patient's condition deteriorated. Most of her problems were as a result of the reduced mobility of her left shoulder and the increased volume of her left arm. These led to limitations in

daily activities, such as self-care (washing, dressing) and household activities, and restricted the patient's ability to ambulate and care for her family. The patient complained about a lack of stamina and constant fatigue.

### Prognosis

The patient was already familiar with the problems caused by her lymphoedema, which helped her to cope with the reduced mobility of her left shoulder. Her positive attitude and faith also helped her to conquer the limitations and restrictions in daily life. The goals established by the patient and therapist were to reduce arm volume, restore the mobility of her shoulder and educate the patient about self-management of the lymphoedema at home.

### Intervention

Initially, the patient was treated at home each

week, but once she had regained stamina, treatment was carried out at the physical therapy clinic. She was able to perform daily exercises at home independently. Visits were originally planned for twice a week but later reduced to once a week, following her recovery. Treatment of the lymphoedema with CDT accomplished a stabilisation of the lymphoedema (Table 3) and the focus shifted to the treatment of the shoulder mobility. Active exercises for muscle strengthening and mobility, stretching techniques (hold-relax) and mobilisation techniques to restore the roll and glide patterns in the shoulder were applied. Resistance band exercises for the upper extremity were added to the home programme to increase her activity level and promote general conditioning. After 12 weeks, the patient was given exercises in the gym; rowing, latt-pull, push forward

**Table 3. Intervention and management timeline.**

Time	Setting	Intervention or management
2008	Hospitalisation	Conservative breast surgery with axillary node dissection left side
2008	Hospitalisation	Eight sessions of chemotherapy and 34 of radiation treatment, followed with 4 years of Herceptin
2011	Outpatient	Developing lymphoedema in the left arm and starting to receive complete decongestive therapy (skin care, manual lymphatic drainage, Manual Lymphatic Drainage (MLD), compression, and exercise) (CDT)
2012	Outpatient	End of CDT treatment
2015	Hospitalisation	Ablatio mammae with axillary node dissection
2015	Hospitalisation	Six sessions of chemotherapy, treatment with Herceptin and Pertuzumab, ceased after 10 months because of cardiac complaints
2015-2017	Outpatient	Lymphoedema and CDT was applied with recurrent periods depending on the complaints of the patient
April 2017	Hospitalisation	Infections with group A <i>streptococci</i> resulting in complaints of nausea, diarrhoea, a painful stomach, fever, and a red, painful, swollen left arm. These were treated with aspiration of an abscess in the axilla and antibiotics (clindamycin and penicillin)
End of April 2017	Outpatient	Start with outpatient nursing care to support her daily activities
May 2017	Outpatient	Start physical therapy (description of the treatment process starts from here). Physical therapy was added to the CDT because of a range of motion (ROM) problem of her left shoulder
September 2017	Outpatient	End of physical therapy

**Table 4. Staging of lymphoedema according to the International Society of Lymphology.**

Stage	Description
0	Subclinical: Swelling is not evident, although lymphatic transport is impaired. May exist for months or years before lymphoedema becomes evident
I	Early onset: Swelling subsides with limb elevation. Oedema may be pitting
II	Limb elevation rarely reduces swelling, and pitting is present. Late in stage II fibrosis begins to occur
III	Tissue is fibrotic and pitting is absent. Skin changes, including thickening, hyperpigmentation, increased skin folds, fat deposits and warty overgrowths, develop

**Table 5. Measurement outcomes.**

Time	NRS	Difference in volume between left and right arm (%)	Flexion of left shoulder (°)
T0	4	15.8	108
T1	2	17	138
T2	0	16.4	161

and a variety of standard exercises with dumbbells, bodybow and gyrorotator.

**Results**

In total, the intervention lasted 21 weeks, of which the last 4 weeks consisted of a treatment frequency of once every 2 weeks. Measurements were recorded at the start of the treatment (T0), after 10 weeks (end of initial phase, start of the maintenance phase) (T1) and at the end of treatment (T2). The pain decreased to an NRS of 0, the volume of the arm stabilised and the flexion of the shoulder increased to 161°. This was in accordance with the satisfaction of the patient. At the end of the intervention, the patient could perform all daily activities without problems, demonstrating that the patient’s goals were achieved (Table 5). Meanwhile, Table 2 shows the responses on the brief ICF Core Set for lymphoedema of the upper extremity. In comparison, it can be seen that the answers on the ICF Core Set keep pace with the measurements and indicate the outcomes of the treatment.

**Discussion**

In this case report, the use of the brief ICF Core Set for lymphoedema of the upper extremity during the treatment with physical therapy, including CDT, was explored. As demonstrated by the patient’s response and in comparison to the outcomes of the measurement instruments, it appears that this Core Set can monitor the course of the treatment well. ICF Core Sets have been used in many scientific studies, but not in the way this case report demonstrates. Although Kus et al (2017) proposed a guideline to implement the brief Core Set for hand conditions, the monitor function, as shown in this case report, has not been used before.

This case report has some limitations. First of all, the goniometry measurements for the shoulder could have been extended with measurements of the external and internal rotation and abduction. This would have given a more complete view of the results of the treatment, because these movements were indeed practiced.

Secondly, retrieving medical history proved difficult and, therefore, only the most vital data were included. Medical history of the patient is important for physical therapists to offer the most appropriate, tailored treatment for the best possible outcome.



Furthermore, the ICF Core Sets for lymphoedema are not yet validated. It is to be expected that use in daily practice will yield imperfections, and based on these imperfections some adjustments will have to be made. Future research with larger groups of patients and healthcare professionals should be conducted to validate the Core Sets. In addition, software that is able to compare outcomes during treatment and provide a graphical overview of patient progression can be developed. Finally, it appeared that the lymphoedema was already stabilised before the therapy was started. There was no pitting-oedema and the patient decided not to wear her sleeve anymore, yet complained about pain and other uncomfortable sensations in the affected arm; the treatment relieved these sensations. This observation can lead to the conclusion that CDT should not only be monitored with volume measurements, but also in conjunction with other measurement instruments to follow the outcomes of the therapy.

## Conclusion

Patient-centred interventions are becoming increasingly relevant and brief ICF Core Sets may contribute to this development. This case study shows that with a patient self-reported tool based

on a brief ICF Core Set, the healthcare professional can understand the ways in which patients' lives are affected by this condition. Subsequently, providing a qualitative insight into the progress of the treatment, which focuses directly on the problematic items.

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