

HUMAN FUNCTIONING IN LYMPHOEDEMA

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Abstract

Background: The description and testing of the different levels of human functioning is essential prior to beginning the treatment of patients with lymphoedema. **Aims:** The International Classification of Functioning, Disability and Health (ICF) offers an international framework for the classification of health and health-related domains. ICF Core Sets are lists of selected ICF categories concerning the important aspects of functioning that are most likely to be affected by a specific disease. These Core Sets make it easier and faster to describe the patient's problems and to define treatment goals. Furthermore, they are available to healthcare providers of all professions, researchers, health insurance companies and policymakers. The objective of this document is to outline the development process for ICF Core Sets for lymphoedema. **Methods:** The ICF Core Sets for lymphoedema will be defined at a consensus conference, on the basis of data derived from the following preparatory studies: a) a systematic review b) a qualitative study c) an expert survey and d) a cross-sectional study. **Results:** Not available at the time of writing. **Conclusions:** The ICF Core Sets for lymphoedema are being designed with the aim of providing a useful standard for both research and clinical practice. **Declaration of interest:** None.

Key words

International Classification
of Functioning,
Disability and Health (ICF)
ICF Core Set
Lymphoedema

The course of lymphoedema is unpredictable and varies among patients. Various types of impairments, activity limitations and restrictions in physical and psychosocial participation can have important consequences for each individual patient with lymphoedema, influencing the treatment programme. Describing and testing the different levels of human

functioning is essential prior to embarking on the treatment of patients with lymphoedema, enabling treatment goals to be defined and adapted to the functioning of each individual patient. To achieve this goal, a framework and classification system is needed, which can serve as an objective, universal yet standardised language understood by health professionals, researchers, policymakers, patients, and patient organisations.

The International Classification of Functioning, Disability and Health (ICF), approved by the World Health Assembly, offers standard terms and schemes for classifying and describing functioning, disability and health in people with lymphoedema. The International Society for Lymphology (ISL) mentions the ICF

in its latest revision of the lymphoedema consensus document (2009). The ICF framework consists of the following components:

- ▶▶ Body structures and functions
- ▶▶ Activities and participation
- ▶▶ Personal and environmental factors.

Personal factors are not yet classified, but the other components contain more than 1,400 ICF categories. This is simply not workable in practice and necessitates the creation of a practical tool to incorporate such a large number of categories. In order to reduce the amount of categories, only those terms/concepts that are the most relevant for individuals with a defined health condition are selected by the experts attending the consensus conference.

Core sets

These summaries are called ICF 'Core Sets', which are practical tools designed for a range of purposes. They allow health professionals to classify and describe an individual's functioning using a universal and standardised language. Therefore, the Core Sets offer a chance for international

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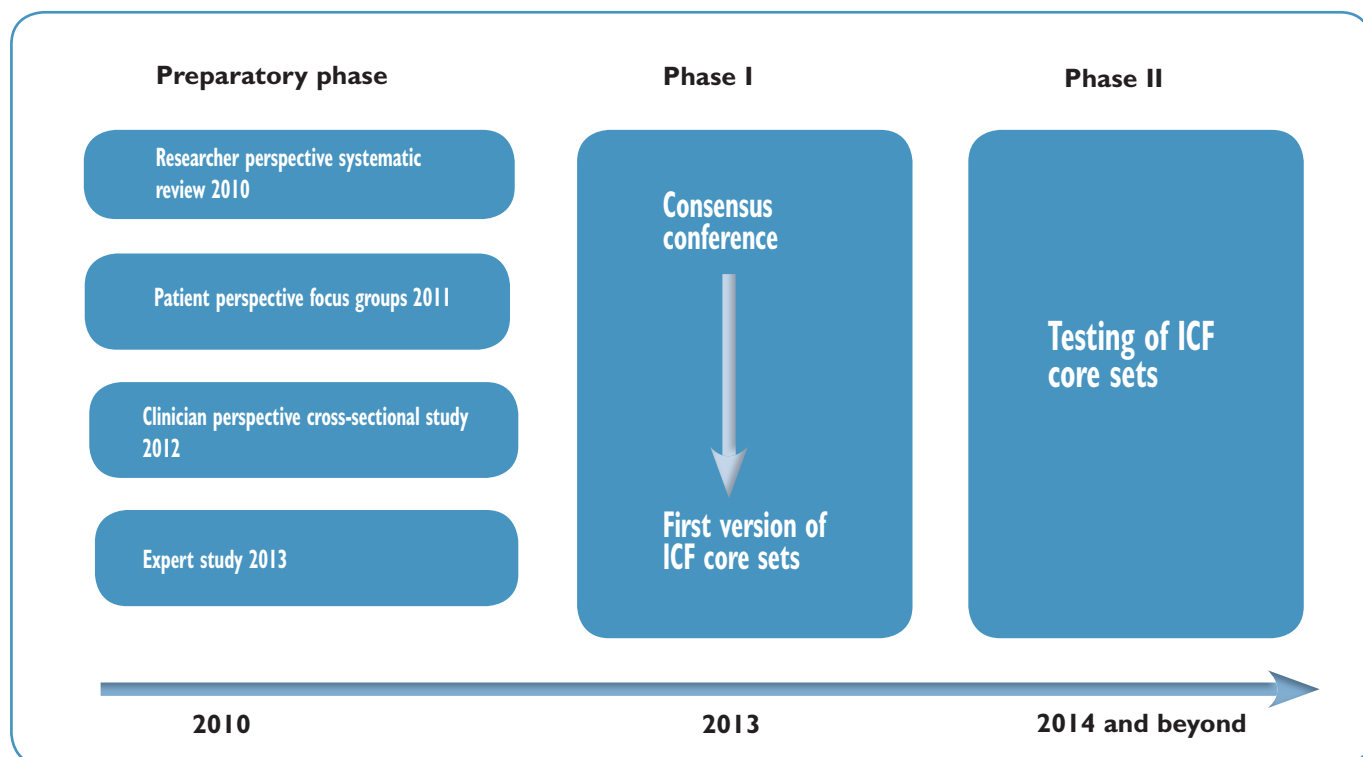


Figure 1. The three phases in the development of the ICF Core Sets for lymphoedema

studies to be conducted and open up the possibility of comparing the impact of different conditions. Moreover, the ICF Core Sets can be used in electronic healthcare records.

To date, ICF Core Sets have been developed for several chronic conditions — see Cieza et al (2004), Stucki and Grimby (2004), Üstün et al (2004). For every health condition, both a brief ICF Core Set (for clinical or epidemiological studies), as well as a comprehensive ICF Core Set (for multidisciplinary assessments) has been established. The development of ICF Core Sets for lymphoedema started as a cooperative effort between the Erasmus Medical Centre (Department of Dermatology) in Rotterdam and the Dutch Institute of Allied Health Care in Amersfoort, under the auspices of the WHO Collaborating Centre for the Family of International Classifications (WHO-FIC) in Bilthoven (all in the Netherlands).

Methods

There are three phases in the development of the ICF Core Sets for lymphoedema: a preparatory phase, phase I and phase II (Figure 1).

Preparatory phase

Within the preparatory phase, studies will be conducted from four different perspectives.

Systematic review: researcher perspective

A systematic review of English language literature will be performed, firstly to identify meaningful concepts reported in studies published between 2005 and 2010 that involve patients with lymphoedema; then to link these concepts to ICF codes and quantify them to indicate their importance in the literature.

The literature will be retrieved from the Medline, Central, Cinahl, Embase and Pedro databases.

Qualitative study: patient perspective

Focus group interviews will be performed with individuals with lymphoedema to identify the aspects of functioning, disability and health that are important to the individual in question. These will then be listed using the ICF as a reference.

Different focus groups will be interviewed, such as those with upper extremity, lower extremity, midline lymphoedema and those with lymphoedema that may or may not be related to cancer.

Expert survey: expert perspective

An internet-based survey will be performed to gather the opinions of an international pool of experts across various health professions (for example, physicians, nurses, physical therapists and skin therapists) regarding the most relevant aspects to be considered in persons with lymphoedema.

Empirical cross-sectional study: clinical perspective

A cross-sectional study with 400 patients will be performed, firstly to describe functioning, disability, health and the relevant personal and environmental factors of individuals with lymphoedema and then to identify whether problems in functioning can be unequivocally classified using the ICF. This study will be executed partly in Australia in cooperation with Flinders University Medical Centre Lymphoedema Assessment Clinic, Adelaide (Professor Neil Piller).

Phase I

The data collected during the preparatory phase will be presented at a national ICF Core Set consensus conference and experts in the field of lymphoedema will work together to reach a consensus on the most adequate ICF categories to be

included in both the comprehensive and the brief ICF Core Sets for lymphoedema.

Phase II

In Phase II of the project — the testing and implementation of the ICF Core Sets for lymphoedema — an international, cross-sectional, multi-centre validation study involving patients with lymphoedema will be performed, to assess the content validity and feasibility of the comprehensive and brief ICF Core Sets for lymphoedema.

The development of ICF Core Sets for lymphoedema is an inclusive and open process and the project will be conducted in accordance with the ethical principles of the Declaration of Helsinki. Anyone who wishes to participate actively in this process is invited to contact the project co-ordinator (p.viehoff@erasmusmc.nl). The project will be guided by a steering committee comprising the authors of this article.

Discussion

ICF Core Sets for lymphoedema offer a dedicated tool to guide research, with the ultimate aim of improving understanding of functioning, disability and health in people with lymphoedema. Tsauo et al (2010) already proved the usefulness of the ICF in patients suffering from lymphoedema due to breast cancer. They found that data classified with the ICF could well predict the health-related quality of life for these patients.

The ICF Core Sets for lymphoedema will also form the basis for the development of assessment instruments to quantify the severity of the impact of lymphoedema on functioning; to measure change over time; and to measure the effectiveness of interventions. They can also serve as the basis for setting clinical significance thresholds for diagnostic purposes. Finally, it is hoped that this will lead to effective intervention methods that improve functioning and minimise disability among

people with lymphoedema throughout the world. **JL**

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