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ORIGINAL ARTICLE

## Functioning in lymphedema from the patients' perspective using the International Classification of Functioning, Disability and health (ICF) as a reference

PETER B. VIEHOFF<sup>1</sup>, PETRA D. C. GIELINK<sup>2</sup>, ROBERT J. DAMSTRA<sup>3</sup>, YVONNE F. HEERKENS<sup>4,5</sup>, DORINE C. VAN RAVENSBERG<sup>4</sup> & MARTINO H. A. NEUMANN<sup>1</sup>

<sup>1</sup>Department of Dermatology, Erasmus Medical Centre, Rotterdam, The Netherlands, <sup>2</sup>Dutch Society of Physical Therapy within Lymphology, Amersfoort, The Netherlands, <sup>3</sup>Dutch Expert Centre for Lympho-vascular Medicine, Nij Smellinghe Hospital, Drachten, The Netherlands, <sup>4</sup>Dutch Institute of Allied Health Care, Amersfoort, The Netherlands and <sup>5</sup>HAN University of Applied Sciences, Research Centre for Rehabilitation, Work, and Sports, Nijmegen, The Netherlands

### ABSTRACT

**Purpose.** To identify and quantify meaningful concepts in lymphedema from the patients' perspectives using the International Classification of Functioning, Disability and Health (ICF).

**Methods.** Six focus group interviews in five different centers were organized, audiotaped, transcribed verbatim and analyzed.

**Results.** A total of 2681 relevant ICF linkings were performed with the focus group data, resulting in 130 different second-level categories. Of these 130 second-level categories, 41 (31.5%) categories were categorized as Body Functions, 20 (15.5%) as Body Structures, 41 (31.5%) as Activities and Participation, and 28 (21.5%) as Environmental Factors. Overall, the most important issues according to the patients were the use of hosiery and bandages, support and relationships, and the shape of structures related to movement.

**Conclusion.** Based on their experiences with lymphedema, patients reported activity limitations and participation restrictions combined with impaired body functioning. Anatomical changes (Body Structures) were also often mentioned as a problem in daily life. Environmental factors may act as a barrier or facilitator for patient functioning. The ICF provides a valuable reference to identify concepts in statements from lymphedema patients. The results of this research will be used in the development of ICF Core Sets for lymphedema.

Lymphedema is a chronic condition that can lead to physical functioning problems, often resulting in distress [1] and loss of quality of life [2,3]. Lymphedema presents clinically as swelling given the imbalance between interstitial filtration and fluid and protein discharge caused by compromised lymphatic system transport capacity. This condition may occur in upper and lower limbs as well as the midline (head, neck and thorax) and can be subdivided into primary and secondary lymphedema [4]. Primary lymphedema, a congenital and sometimes hereditary disease, may exist at birth; however, most cases of primary lymphedema are manifested during puberty [4]. The lymph vessels and/or nodes are not well constructed

or do not function properly because of gene mutations [4]. This condition is most commonly observed in the legs but can occur throughout the entire body, including the genital region. Secondary lymphedema results from lymph vessel and/or node damage, which occurs as a complication of oncologic surgery and/or radiotherapy, infections or trauma [5]. According to a WHO report, approximately 120 million people in 72 countries were infected with a parasite (lymphatic filariasis) in 2010 [6]. Of these infected individuals, 15 million people suffered from the consequent lymphedema manifestations (filarial elephantiasis). Podoconiosis is endemic non-filarial elephantiasis due to long-term barefoot exposure to irritant volcanic

soils in tropical Africa [7]. Lymphedema epidemiology is not exactly known because it is not a well-registered disease. The number of patients worldwide is estimated to be approximately 140–250 million [5].

#### *Symptoms of lymphedema*

If untreated, lymphedema leads to irreversible tissue changes, a high risk of infection and feelings of heaviness and tightness; in addition, patients report that jewellery or clothes feel uncomfortable or tight on the affected body parts [8–10]. These features lead to impairments, such as a decreased range of movement of the limb involved, as well as to limitations in walking, personal care, domestic life, occupation and socialization [7]. Altered body shape, often leading to stigmatization, as well as the need to use garments or bandaging daily, make acceptance difficult for the patient as well as his/her family [11].

#### *Treatment*

Lymphedema therapeutic options include conservative and operative modalities and should be fine-tuned to the patient's living circumstances, including work and home environments, as well as to personal factors, such as age, co-morbidities, (malignant) disease prognosis, psychosocial aspects, and physical potential. The general goal of conservative treatment is to eliminate edema; by compression therapy in combination with manual lymph drainage (MLD) [12], exercises, proper weight reduction and weight control [13], and special skin care to prevent infection [14]. When maximal initial therapeutic result is achieved, the emphasis of the treatment will be on enhancing patient self-management, including strict compliance in wearing compression garments (bandages, wraps or hosiery) [12]. In severe lymphedema stages, circumferential suction-assisted lipectomy can be applied to alleviate irreversible alterations, such as adipose tissue formation and fibrosis [15]. In 2012, the International Lymphedema Framework [ILF] published the 'best practice document' for the management of lymphedema [16]. It proposes a comprehensive lymphedema service based on the chronic care model and use of the International Classification of Functioning, Disability and Health (ICF) as a vehicle for determining and delivering a patient's needs [16].

#### *ICF*

The ICF provides a comprehensive framework of human functioning as well as a classification system, based on a bio-psychosocial model [17,18]. In addition, it offers a universal language understood by

health professionals, researchers, policy makers, patients, and patient organizations.

The ICF consists of two separate parts. Part 1 addresses functioning and is composed of three components: 'Body Functions', 'Body Structures', and 'Activities and Participation'. Part 2 addresses contextual factors and is composed of two components: 'Environmental Factors' and 'Personal Factors'. However, 'Personal Factors' are not described as a classification in the ICF yet, because of the significant social and cultural variation [11].

Each ICF category is assigned an alphanumeric code, a letter that refers to the classification components (b: Body Functions, s: Body Structures, d: Activities and Participation, and e: Environmental Factors). Each letter is followed by a number or numbers starting with the chapter number (one digit) and followed by second-level specifications (three digits) and further third- and fourth-level specifications (four and five digits), where applicable.

Although its classifications with more than 1400 categories can serve as a reference, the ICF is not easily applicable in clinical practice. For this reason, tools, such as ICF Core Sets [17,18] (a core set is an ICF selection developed for a specific diagnostic group), make the ICF useful for healthcare providers [19]. The Core Sets facilitate the use of ICF-terminology to describe the functioning profile of a patient (a 'functional' diagnosis) and the formulation of treatment goals. Description uniformity is needed to compare data for the evaluation of treatment efficacy and to collect data for research. The ICF Core Sets may be used during the process of clinical reasoning and to record the results of clinical reasoning and treatment in electronic healthcare records.

Today, ICF Core Sets have been developed for various burdensome chronic conditions [18,20–22] and since lymphedema is a serious, chronic and worldwide problem in health care, there is a great need for specific Core Sets for this disease [3,23,24]. The development of Core Sets for lymphedema consists of several preparatory studies leading to an international consensus conference. To obtain a complete spectrum of the effects of lymphedema, these studies have different points of view, i.e. the researcher, the clinician, the patient and the international expert.

#### *Aim of the study*

The aim of this study is to determine relevant aspects of functioning as well as relevant environmental and personal factors from the lymphedema patients' perspective and to quantify these, using the ICF.

## Methods

### Design

A Dutch multicenter qualitative study using focus group interviews was conducted as part of a larger project on the development of ICF Core Sets for lymphedema [25]. Patients were recruited from five different centers during 2012–2013. Stucki and Cieza [17] developed a method to establish ICF Core Sets for specific conditions. The development of ICF Core Sets for lymphedema follows this procedure. The study was approved by the Ethics Committee of the Erasmus Medical Centre in the Netherlands and performed in accordance with the Declaration of Helsinki.

### Participants

To obtain a comprehensive understanding of the continuum of clinical care, patients from various treatment stages (control, after first contact, during initial treatment phase and maintenance phase) were included. As lymphedema occurs in various locations and results from various causes, six different focus groups were used, each with 3–8 participants. These groups consisted of patients with: (A) lymphedema with non-oncology background (mixed locations), (B) lymphedema with oncology background (mixed locations), (C) lymphedema of the upper limb (mixed causes), (D) lymphedema of the lower limb (mixed causes), (E) lymphedema in the genital region (mixed causes), and (F) lymphedema in the head and neck region caused by cancer-treatment.

All participants had to meet the following inclusion criteria: the individual 1) had a diagnosis of lymphedema determined by a physician; 2) was older than 18 years; 3) was informed of and understood the purpose and rationale of the study; and 4) signed the patient consent form. Before they participated, patients had to fill in a form with questions about socio-demographic items and comorbidities and they had to range their perceived lymphedema severity on a scale from zero to ten.

### Questions

The following open-ended questions, based on ICF components, were used in the focus groups [26–28]:

1. If you think about your body and mind, what does not work the way it is supposed to? (Body Functions)
2. If you think about your body, in which parts are your problems located? (Body Structures)
3. If you think about your daily life, which problems do you experience performing the

activities or things you want or are necessary? (Activities and Participation)

4. If you think about your environment and living conditions, what do you find helpful or supportive? (Environmental Factors-facilitators)
5. If you think about your environment and living conditions, what barriers do you experience? (Environmental Factors-barriers)
6. If you think about yourself, what is important about you and the way you handle your disease or the problems associated with your disease? (Personal Factors)

### Data collection

The same moderator [a member of the Dutch Society for Physical Therapists within Lymphology (NVFL)] led the focus groups. When collecting information about the nature and course of the study, the moderator emphasized that the individual retained the right to refuse participation at any time without any treatment consequences. Each focus group discussion was digitally recorded and transcribed verbatim. When the transcription was completed, the members of each focus group had the opportunity – by email – to agree with the contents of the transcription (member check). If not, alterations were made until there was agreement.

### Data analysis

The data analysis was conducted in four steps and followed the method of ‘meaning condensation’ [29]. In the first step, the transcribed focus group data were read to obtain an overview of the collected data. In the second step, the data were divided into ‘meaning units’, and the theme that dominated a meaning unit was determined. A ‘meaning unit’ was defined as a specific unit of text, either a few words or a few sentences, with a common theme [30]. The text was divided as soon as the researcher discerned a shift in the meaning [29]. In the third step, ‘meaningful concepts’ contained in the meaning units were identified. A ‘meaningful concept’ (MC) was defined as a unit of text that conveys a single theme [31]. A meaning unit could contain more than one MC. This procedure was conducted using the Kwalitan software program, version 6.02.

In step four, each MC was linked to one or more ICF categories according to published linking rules [32,33]. Linked ICF categories are defined as relevant concepts of functioning for individuals with lymphedema. The following concepts cannot be classified using the ICF: personal factors (indicated with ‘pf’), health conditions (‘hc’), concepts related to the ICF but cannot be assigned a particular component

or code (not definable 'nd'), and concepts beyond the ICF framework (not covered 'nc'). The MCs were linked independently of the six questions (e.g. codes referring to the Body Functions component could also arise when the group answered one of the five other questions). After each focus group, the linked ICF categories were added to a list of ICF categories selected so far from earlier studies [34].

#### Quality of data

To assure reliability, two health professionals (PV and PG) separately performed step three and four in the first focus group to achieve agreement concerning the implementation of the linking rules for this specific health condition. The procedure was performed according to the method proposed by Stucki and Cieza for the development of ICF Core Sets [32,33]. Afterwards, the MCs and linking processes identified by the two health professionals were compared. The degree of agreement between the two health professionals (PV and PG) regarding the identified MCs as well as the linked ICF categories in the first focus group was calculated by kappa statistics. The kappa coefficient values generally range from 0 to 1, where 1 indicates perfect agreement and 0 indicates no agreement beyond what is expected by chance alone. A kappa value of 0.6 or greater is considered sufficient [35]. Disagreement was resolved by structured discussion.

#### The data analysis for all focus groups

After analyzing data from the first focus group and ICF linking, three individuals independently linked all MCs from all focus groups to the ICF (PV, YH, DvR). Disagreement was resolved after structured discussion to create consensus for a final version of the linked ICF categories. This extra ICF coding (agreement) was performed to obtain the best possible ICF linking from the patients' perspectives.

The degree of agreement concerning the linking of all MCs between the main researcher (PV) and the other researchers (YH, DR) was subsequently assessed by kappa statistics.

## Results

#### Description of the focus groups patients

A total of 31 patients with a mean age of 55 years participated in six focus groups; the majority of the participants were female (67.7%). Of the 31 patients, the lymphedema location included seven exclusive upper limb cases, 11 exclusive lower limb cases, five exclusive midline cases and eight cases displaying a combination of locations (6 lower limb-genital region cases and two upper limb-breast cases). In total, 18 patients reported a history of cancer, and 13 reported no history of cancer (i.e. primary lymphedema). Lymphedema severity, as judged by the participants themselves, was the highest in the lymphedema group with an oncologic cause (6.5 on a scale of 0 to 10) and the genital lymphedema group (6.0). Further details of the patient characteristics are shown in Table I.

#### Data analysis and meaning units

The following meaning units were observed in most of the groups:

1. Lymphedema is accepted as a burden that one has to learn to live with.
2. Hosiery and bandages are viewed as barriers to daily life that also alleviate the disability.
3. Persons with lymphedema experience problems with clothing choices.
4. Swimming is an activity that provides relief during the activity itself. However, patients do not choose to go to the beach or swimming pool, due to either feelings of shame or problems with their stockings.

Table I. Patient characteristics.

| Variables                                     | Total (n = 31) | A (n = 5)   | B (n = 6) | C (n = 5)   | D (n = 6)     | E (n = 6)     | F (n = 3) |
|---|----------------|-------------|-----------|-------------|---------------|---------------|-----------|
| Age in years                                  | 55 (13.6)      | 37.8 (8.5)  | 61.1 (13) | 61.6 (12.9) | 51.5 (12.2)   | 56.2 (11.9)   | 65.3 (3)  |
| Women:men                                     | 21:10          | 5:0         | 6:0       | 5:0         | 5:1           | 0:6           | 0:3       |
| Duration of lymphedema in months              | 124 (160)      | 186 (132.9) | 39 (20.1) | 49.4 (50.2) | 218.5 (231.8) | 184.3 (205.2) | 5.3 (1.5) |
| Upper limb:lower limb:midline:combination     | 7:11:5:8       | 0:5:0:0     | 2:2:0:2   | 5:0:0:0     | 0:4:0:2       | 0:0:2:4       | 0:0:3:0   |
| Seriousness of lymphedema on a 11-point scale | 5.7 (2.3)      | 5 (1.2)     | 6.5 (0.5) | 5.6 (3)     | 5.5 (2.3)     | 6 (4)         | 5.3 (2)   |
| Employment                                    | 15             | 4           | 2         | 3           | 3             | 2             | 1         |

(A) Lymphedema with non-oncology background (mixed locations), (B) lymphedema with oncology background (mixed locations), (C) lymphedema of the upper limb (mixed backgrounds), (D) lymphedema of the lower limb (mixed backgrounds), (E) lymphedema in the genital region (mixed backgrounds) and (F) lymphedema in the head and neck region. ( ), standard deviation.



5. Most lymphedema (swelling) problems are experienced during summer. However, some patients report fewer problems in summer compared with winter.
6. Contact with health professionals is rather ambivalent. The patients report good and bad experiences. In addition, the patients feel as if health professionals are ignorant and down-play lymphedema, because they do not really know what it means to have lymphedema.
7. Numbness and hardened skin are the most frequently mentioned problems concerning the skin.
8. Patients report that distress has a negative effect on lymphedema; stress worsens lymphedema and is a risk factor for erysipelas.
9. Contact with fellow sufferers is worthwhile.
10. Patients with lymphedema localized in the genital area as well as in the head and neck region are most likely to discuss the impact and consequences of operations compared with the other groups.
11. Patients with lower limb lymphedema experience swelling that always begins in the feet and expands up the leg, whereas patients with upper limb lymphedema describe swelling at various sites of the arm.
12. Individuals with lymphedema in the lower limbs mention pain more often than those with lymphedema in other locations.
13. The group with genital lymphedema uses specific devices, such as general lymphedema devices or devices that support urination (e.g. the Whittaker pouch and self-made constructions to regulate urination), most often compared with other groups.

#### *Linking MCs to the ICF*

Based on the focus group data, a total of 2681 relevant ICF linkings were performed. In total, 12 first-level categories, 78 second-level categories, 146 third-level categories, and seven fourth-level categories for ICF linkings were identified. For clarity and readability, the third- and fourth-level categories were merged into the second-level categories, resulting in 130 different second-level categories. Of the 130 second-level categories, 41 (31.5%) categories were identified as Body Functions, 20 (15.5%) as Body Structures, 41 (31.5%) as Activities and Participation, and 28 (21.5%) as Environmental Factors. Of the 282 MCs that could not be given an ICF code (9.5% of all MCs), 135 (48%; 4.6% of all MCs) were coded as Personal Factors, 9 (3%; 0.3% of all MCs) were coded as 'nc', 12 (4%; 0.4% of all MCs) were coded as 'nd', 7 (2%; 0.2% of all MCs)

were coded as 'nd-gh', and 119 (43%; 4% of all MCs) were coded as 'hc'.

#### *Body Functions*

Supplementary Table I (available online at <http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.952389>) shows the first- and second-level categories identified for the Body Functions component. The top five frequently mentioned categories were 'b435, Immunological system functions' (impairments in the lymphatic system); 'b152, Emotional functions' (emotions such as fear, anger, joy); 'b280, Sensation of pain'; 'b126, Temperament and personality functions' (including psychic stability, confidence and optimism); and 'b840, Sensations related to the skin' (including itching and tingling). This pattern is observed in most of the groups, with a few differences. In the group with lymphedema in the head and neck region (F), the most mentioned category is 'b510, Ingestion functions'. In the group with upper limb lymphedema (C), the most frequent category is 'b455, Exercise tolerance functions'. Various quotes from patients describing some of these categories are found below.

"... heavy feeling and tiredness. Especially in the summer when it is hot, you get the feeling that your leg is swelling and you can't move forward. Previously I did not have that problem but ever since the edema it bothers me" [patient from group B lymphedema with oncology background (mixed locations)].

"...it looks as if mental things have more influence on the edema than physical. When, for instance, I witness a funeral the edema gets worse" [patient from group B lymphedema with oncology background (mixed locations)].

#### *Body Structures*

Supplementary Table II (available online at <http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.952389>) displays the first- and second-level categories identified for the Body Structures component. In this component, the top five mentioned categories were 's750, Structure of lower extremity'; 's730, Structure of upper extremity'; 's630, Structure of reproductive system'; 's710, Structure of head and neck region'; and 's760, Structure of trunk'. In the genital lymphedema (E) group, the most mentioned category was 's630, Structure of reproductive system'. In group F (head and neck lymphedema), the most mentioned category was 's710, Structure of head and neck region'. The following quotes illustrate the Body Structures component:

“...but in fact I already have thick feet and swollen legs since 1978” [patient from group D lymphedema of the lower limb (mixed causes)].

“...but it is especially the deformation of my face. That is very annoying. It does not bother me much, except that my lips get swollen. They do not occlude enough and you make a mess when drinking” (patient from group F lymphedema in the head and neck region).

“...when I was being operated and my lymph nodes were removed, they told me that there was a chance I could get swollen legs. But about genital lymphedema they did not say anything. You had to find that out afterwards by yourself” (patient from group E lymphedema in the genital region).

#### *Activities and Participation*

Supplementary Table III (available online at <http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.952389>) indicates the first- and second-level categories identified for the Activities and Participation component. The top five categories identified were ‘d920, Recreation and leisure’; ‘d415, Maintaining a body position’ (lying, sitting, standing, etc.), ‘d570, Looking after one’s health’ (ensuring comfort, maintaining health and managing diet and fitness); ‘d450, Walking’; and ‘d475, Driving’. In focus group C (upper limb lymphedema with mixed backgrounds), ‘d640, Doing housework’ occurred most frequently, whereas ‘d415, Maintaining a body position’ occurred most frequently in the genital lymphedema group (E).

Typical quotes from the Activities and Participation component are found below:

“...you are always busy considering your legs. Because you can’t work and practice a sport and doing things at home as well” [patient from group A lymphedema with non-oncology background (mixed locations)].

“...the problem with driving is the pain in your legs. But since I have a car with cruise control it doesn’t bother me anymore” [patient from group D lymphedema of the lower limb (mixed causes)].

Some statements regarding the impact of genital lymphedema (group E patients) are:

“...I can’t walk very far, I can’t sit for a long time, I can’t lay down and I can’t bend over because I lose my balance and then I fall down on the ground. This is hindering my daily activities, although I try to make the best out of it”.

“...I also can’t urinate in a normal way. At home I use an urinal and when I leave home I always take little cups with me because it sprinkles everywhere. I use a diaper and every morning I bandage my scrotum”.

#### *Environmental Factors*

Supplementary Table IV (available online at <http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.952389>) displays the first- and second-level categories identified for the Environmental Factors component. The categories that occurred most often were ‘e115, Products and technology for personal use in daily living’ (non-adapted items include clothes, shoes, textiles, furniture, and tools; adapted items include stockings and prostheses); ‘e580, Health services, systems and policies’ (all services, systems and policies for the prevention and treatment of health problems that provide medical rehabilitation and promote a healthy life style); ‘e355, Health professionals’; ‘e310, Immediate family’; and ‘e110, Products and substances for personal consumption’. The examples below illustrate these findings:

“...what really works is a hula-hoop. It helps draining the lymphedema in my legs when I use it daily” [patient from group D lymphedema of the lower limb (mixed causes)].

“...the insurance company does not always co-operate. They compensate two pairs of stockings within 12 months, which is not sufficient at all. I just have to pay them myself” [patient from group E lymphedema in the genital region (mixed causes)].

#### *Personal Factors*

Personal factors can be broadly divided into socio-demographic factors (including gender and race), personal living situations and coping strategies.

Various quotes applicable to these factors are found below:

“...I don’t know how to explain it. Everybody would like to assist you but in some sort of way you live in a cocoon. You go your own way and you seclude yourself from them. There will be a moment in time that you will realize that you can’t do it alone, but I am not at that point yet” [patient from group A lymphedema with non-oncology background (mixed locations)].

“...always being busy. With a group of friends practicing sports and afterwards drinking a pint. Not sitting at home and thinking about the

problems” [patient from group E lymphedema in the genital region (mixed causes)].

#### *Not covered or definable items*

Statements that were not covered or definable by the ICF were, i.e.: ‘daily life’, ‘handicap’, ‘dead’, ‘tissue’ and ‘being sickly’.

#### *Quality of data*

*Inter-coder reliability in the first focus group (PV and PG).* The inter-coder agreement for the determination of MCs was 63.8% (kappa 0.31). Regarding the linking of MCs to the ICF, the inter-coder agreement was 73% (kappa 0.46). As previously mentioned, the MCs determination and the ICF linking process were performed simultaneously. Disagreements most often originated from the fact that both researchers possess different points of view (e.g. both researchers consistently coded the same MC in different ways).

*Inter-coder reliability for all focus groups (PV, YH and DvR).* The inter-coder agreement for ICF linking of the meaningful concepts between PV and YH was 75% (kappa 0.72) and 55% (kappa 0.49) between PV and DR. In this case, YH and DR linked MCs with unknown contexts (i.e. the coders did not know which focus groups supplied the MCs). These MCs could be interpreted in various ways. Examples are MCs like: “I am not a man anymore”, “Visit” and “Stress”. In addition, these statements are also examples of the previously cited problem of coding the same MC in different ways.

## **Discussion**

As part of the development process for ICF Core sets for lymphedema, the purpose of this study was to determine relevant aspects of functioning as well as environmental and personal factors from the perspective of lymphedema patients. Based on their experiences with lymphedema, patients predominantly faced activity limitations and participation restrictions (31.5% of MCs) combined with impaired body functions (also 31.5% of MCs). Environmental factors were indicated in 21.5% of MCs, and these factors were considered to act as barriers (e.g. hosiery) or facilitators (e.g. spouses).

Anatomical changes (body structure impairments) were given less attention and identified in 15.5% of MCs.

From the focus groups it can be derived that lymphedema is a chronic health condition, which needs constant medical care and attention. In many parts of the world lymphedema is treated in rehabilitation

settings. A common complaint of patients is that they have a chronic medical problem and need ongoing medical care and not only one period of treatment in a rehabilitation setting. The findings in this study support this patients’ point of view. Although recent guidelines [12,36] put more emphasis on self-management and education of the patient to become less dependent on health care, regular monitoring and support is advised. Depending on the severity of the condition and the level of self-management, patients will need more or less frequent treatment and life-long monitoring.

#### *Meaning units*

Problems with accepting lymphedema were mentioned in every group; however, these problems were cited less frequently in primary lymphedema patients. This finding is likely attributable to the fact that these patients have had more time to accept their disease as they have experienced lymphedema longer than the other groups. Many patients stated that movement, particularly swimming, relieves lymphedema symptoms during the activity itself. Consistent with this finding, Tidhar et al. [37,38] designed a water exercise program to improve mobility and lymphatic drainage. Most swelling problems occur during summer; however, some patients experience fewer problems in summer than winter. Higher summer temperatures, resulting in greater subcutaneous fluid in the suprafascial compartments by enhanced capillary filtration, leads to more swelling. The available literature does not explain why warm weather provides relief to some patients.

The most frequently mentioned skin complaints consist of a hardened and numb feeling. This complaint could be a negative side effect of radiotherapy; however, various patients with primary lymphedema who have not received radiotherapy cite similar problems.

Patients with lower limb lymphedema complain more about pain than people with lymphedema in other locations. This observation can be explained by the fact that, due to gravitation, more pressure exists in the lower versus upper limbs.

#### *Body Functions*

The focus group participants reported a variety of impairments in Body Functions. All of the chapters in this component were covered, especially the chapters regarding mental functions as well as functions of cardiovascular, hematological, immunological and respiratory systems. The mental effects of lymphedema pertain to topics that were also reported in previous studies, such as impairments in body image



[39,40], distress [41,42], and more fatigue [42]. Person et al. [43] recommended that physiological distress management should serve as a significant component of lymphedema management programs in developing countries. Although impairments in sexual functions can play an important role [44], these problems were only mentioned in the genital lymphedema group. It is possible that these sexual problems are underreported and will be more easily expressed in one-to-one interviews.

### *Body Structures*

Altered body shape is a problem discussed in the groups and found in the Body Structures component. The shape of the lower limb was particularly cited as problematic. This finding was also mentioned in earlier publications [39,40,42].

### *Activities and Participation*

All categories of the Activities and Participation component were mentioned. Mobility items were mentioned most often, followed by self-care, recreation and leisure, and domestic life. Other studies partially support these findings. Self-management to prevent lymphedema worsening is emphasized in the focus groups [11,45]; however, the impact on recreation and leisure was not found in earlier literature. The patients also stated that they had problems with creating and maintaining interpersonal relationships, which made them isolated in society. This isolation was described in various studies [41,46,47]. In the focus groups, remunerative employment was only partially discussed; this observation is likely because half of the patient population was not working at the time of the interview. It appears that lymphedema has a minor impact on work in Western countries compared with developing countries [47,48].

### *Environmental Factors*

The top three mentioned environmental factors are Products and technology, Support and relationships, and Health services, systems and policies. The literature supports these findings.

The impact of bandages and hosiery is reported in the literature. Although studies on compression garments are scarce or only described using small patient groups, Janda et al. [49] highlighted the financial burden of compression garments (only 15 patients). Frid et al. [39] mentioned the loss of autonomy as patients are dependent on nursing staff for dressing. Sawan et al. [50] concluded that the use of hosiery had no impact on health-related quality of life (14 patients). The findings of Sawan et al. are not

supported by the patients of these focus groups. In every focus group bandaging and hosiery were discussed in detail and it was a recurring topic. Overall the conclusion is that it is a burden, but one with which they cannot live without. Presumably it does affect their health-related quality of life. Thus, the influence of this environmental factor should be more broadly examined in the future.

In the search for a correct diagnosis and effective treatment [45], interactions with other persons are perceived as both positive and negative, often leading to stigmatization [39,40,47,48,51]. Although stigmatization was mentioned in some Western studies, the impact of its consequences likely plays a greater role in developing countries [48].

Health professionals are perceived as lacking education in this respect and give too little post-intervention support [40,46,48,51]. From these patients' observations it can be derived that lymphedema is not well known and sometimes underestimated by health professionals. So there is a need for more education for those who could encounter lymphedema (e.g. general practitioners and surgeons), especially when working with oncology patients. Financial support from government and insurance companies is however lacking [51].

### *Personal Factors*

In the qualitative research literature, personal factors play an important role in describing the coping strategies of lymphedema patients [11,39,46,48]. The outcomes of this study support these findings. Unfortunately, personal factors cannot be coded with the ICF; however, various suggestions on the subdivision and classification of personal factors have been made [52–54].

### *Limitations of the research*

Although several meaning units were identified and most of the ICF domains were addressed, various limitations to this study exist. By merging the third and fourth ICF levels into the second level, some specific codes (corresponding with MCs) are not expressed in the analysis. These codes were presented at the concluding consensus conference, which is the last step in the Core Sets development. Based on the findings of this research, it cannot be concluded that all of the ICF categories that were identified are equally relevant and represent all forms of lymphedema because the focus groups were comprised of lymphedema patients with various etiologies and clinical locations. Although the researchers attempted to obtain data on a variety of health conditions, the predominance of cancer-related lymphedema (18 of

the 31 patients) can serve as a bias. Cross-cultural variation was not considered because the study was conducted in one (Western) country, the Netherlands. Only one person with a different cultural background was part of the focus group. Lymphedema can be inborn; by excluding individuals younger than 18 years, some age-related issues were potentially missed.

This research is part of the preparatory studies for the development of ICF Core Sets for lymphedema and provides quantitative data for the consensus conference, where the final version of the Core Sets was formulated [25]. This study uses a qualitative approach, seeming the best method to determine the patients' point of view. For the presentation at the international consensus conference, being the final part of the development of the ICF Core Sets, the qualitative data had to be made quantitative. This study followed the method of Stucki and Cieza [14] in which this is stated. A lot of research has followed this procedure ever since [21,28–30].

Furthermore, the research bias could result from the fact that the six open questions are leading, referring to specific ICF components. However, all participants could freely speak about issues important for them during the focus group discussions. Above all, it is important to take into account that the qualitative approach in this study was performed to identify the broadest possible range of problems, also to provide a decision base for the consensus process in the development of ICF Core Sets for lymphedema.

The low kappa value of the inter-coder reliability between PV and PG (0.46) and PV and DvR (0.49) compared with other studies (e.g. Geyh et al. [55]; range: 0.46–0.84) can be partly explained by the fact that the kappa values were calculated after a fully independent formulation of MCs by two persons and concept linking to ICF-codes. Inter-individual differences can result from variation in the identification of MCs as well as the selection of ICF-codes. In the study of Geyh et al. [55], the kappa values were calculated after consensus was reached for the MCs.

Compared to the literature review [34], which was conducted as part of the lymphedema ICF Core set development, some points of interest are worth mentioning. Although Randomized Clinical Trials (RCTs) and qualitative research are commonly considered the most valuable type of research, qualitative lymphedema research is limited. Furthermore, in the existing lymphedema RCTs, little attention is given to the following ICF chapters: Functions of the skin and related structures, Recreation and leisure, and Support and relationships. However, patients indicated that they consider these topics important. These findings should be considered when composing the first version of the lymphedema

Core Sets. They also should be respected by health care providers and should be considered as variables in future RCTs.

## Conclusion

Systematic research on the effects of lymphedema from a patient's point of view using the ICF has not been previously performed. This study provides sufficient data for the development of Core Sets for lymphedema using the bio-psychosocial model. The data help to describe the functioning of lymphedema patients using international standards. Various lymphedema locations were examined, indicating outcome differences and similarities between the groups. Patients with lower limb lymphedema tend to have more pain than other patients. Overall, the most important issues to the patient were the use of hosiery and bandages, support and relationships, and the shape of structures related with movement. The impact of hosiery and bandages on daily life in particular needs more attention in clinical practice and therefore further investigation is needed to obtain objective measurements on this topic.

Finally, from these focus groups it appeared that lymphedema is a chronic health condition which needs ongoing medical care and attention.

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### **Supplementary material available online**

Supplementary Tables I–IV. (available online at <http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.952389>).