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ORIGINAL ARTICLE

Identification of relevant ICF (International Classification of Functioning, Disability and Health) categories in lymphedema patients: A cross-sectional study

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ABSTRACT

Background. To describe functioning and health of lymphedema patients and to identify their most common problems using the International Classification of Functioning, Disability and Health (ICF) as part of the preparatory studies for the development of ICF Core Sets for lymphedema.

Methods. Cross-sectional study in a population of lymphedema patients (n = 200), undergoing treatment in a Dutch lymphedema-specialized hospital. The second-level categories of the ICF were used to collect information on patients' problems in daily functioning.

Results. The mean age of the study group was 56 years (22–84). In total 78.5% of the patients were female. The most frequent mentioned items were: In the Body Functions component: muscle power and mobility of joints, in the Activities and Participation component: doing housework, and changing and maintaining a body position, in the Environmental Factors: Health professionals, who can act as both facilitators and barriers. Interestingly, patients assessed their health more positively than health professionals do.

Conclusion. By using the ICF, a considerable part of the broad spectrum of problems in functioning of lymphedema patients was reported.

Congenital (primary) or acquired (secondary) lymphedema can affect patient's quality of life both physically and psychosocially [1]. It is a chronic condition which is often progressive in time [2]. Factors influencing the quality of life are pain, swelling and disturbed feelings in the affected body parts [2]. Patients can experience a change in body image or psychological stability, limitations in activities and restrictions in participation and all this can depend on the localization of the lymphedema as well as on personal and environmental factors [3].

Describing the functioning, disability and health of a lymphedema patient, including facilitators and barriers, is an important part of understanding the life of a lymphedema patient and will help to define treatment goals.

The International Classification of Functioning, Disability and Health (ICF), is the World Health Organization (WHO) framework for measuring functioning and disability at both individual and population levels and is approved by the World Health Assembly [4].

The ICF can be used for many different purposes such as:

1) a scientific basis for understanding and studying health and health-related states, outcomes and determinants;
2) a common language for describing health and health-related states in order to improve communication between different users, such as healthcare workers, researchers, policy-makers

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and the public, including people with disabilities;

3) a tool for comparison of data across countries, healthcare disciplines, services and time;
4) a systematic coding scheme for health information systems [4].

More than 1400 categories are described in the ICF, which is not very applicable in daily practice. Working with ICF Core Sets for a specific health condition (Comprehensive Core Set of 75-150 categories; Brief Core Set of 10–15 categories) allows the ICF to be a practical tool for health professionals [5].

Since there are no ICF Core Sets for lymphedema, a project was started, following the procedures of Cieza et al. [6]. According to these procedures, four preparatory studies were performed from: 1) the researchers' perspective (systematic review); 2) the patients' perspective (qualitative study); 3) the expert perspective (expert survey); and 4) the clinical perspective (cross-sectional study). These preparatory studies were followed by an international consensus conference, meant for experts in the field of lymphedema to decide on the ICF categories to be included in the ICF Core Sets for lymphedema. This article reports on the results of the cross-sectional study. The objective was to describe the functioning and disability of lymphedema patients and to identify the most common problems in lymphedema using the ICF.

Methods

Study design

The study design was a cross-sectional study among lymphedema patients. Patients were recruited from the department of the Dutch Expert Centre of Lymphovascular Medicine, Nij Smellinghe Hospital, Drachten, the Netherlands between March 2013 and March 2014. This hospital is specialized in the treatment of lymphedema and the patients recruited were either inpatients or outpatients. In accordance with the declaration of Helsinki, a positive vote of the ethics committee was obtained prior to start and informed consent was obtained from all the patients.

Assessment

The ICF has two parts, each containing two separate components. Part 1 covers functioning and disability and includes the components Body Functions (b), Body Structures (s), and Activities and Participation (d). Part 2 covers contextual factors and includes the components Environmental Factors (e) and (non-classified) Personal Factors. In the ICF classification, the letters b, s, d, and e, that refer to the components of the classification, are followed by a numeric code starting with the chapter number (one digit) followed by the second level categories (two digits), and the more detailed third and fourth level categories (one digit each). For this study, the second level categories of the ICF were used. The ICF provides qualifiers which range from 0 to 4 for each category. Each category of the components Body Functions, Body Structures and Activities and Participation was graded with the qualifiers 0 for 'no impairment/limitation/restriction', 1 for 'mild impairment/limitation/restriction', 2 for 'moderate impairment/limitation/restriction', 3 for 'severe impairment/limitation/restriction' and 4 for 'complete impairment/limitation/restriction'. The categories of the component Environmental Factors were graded with 0 for 'No facilitator/no barrier', + 1 for 'mild facilitator' and -1 for 'mild barrier', + 2 or -2 for 'moderate facilitator or barrier', + 3 or -3 for 'severe facilitator or barrier' and + 4 or -4 for 'complete facilitator or barrier'. Additionally, the qualifier '8' had to be used if the available information was not sufficient and '9' if the category was not applicable [7]. The interviewers were instructed to report only limitations and impairment due to the lymphedema. If a patient had a limitation due to comorbidity that was not associated with lymphedema, this did not contribute to the prevalence of the corresponding ICF category and was given the qualifier 'C'. As it was not patient-friendly to question all categories of the ICF only those second-level ICF categories, that came forward from a previous literature study of lymphedema-specific questionnaires [8] were used for this study (i.e. 102 categories). A standardized form collected socio-demographic variables and comorbidities. Additionally, health professionals had to rank the patients' health and the magnitude of the problems of the functioning of the patient in everyday life on a scale ranging from 0 (no problem) to 10 (complete problem). Patients rated their health status in the same way as well.

Data collection procedures

Patients were recruited and interviewed by health professionals from several specialities trained in the principles of the ICF. Each health professional was given a personal training how to obtain the best information by performing a patient interview. Before an interview started, each patient's medical record sheet was checked and relevant information on socio-demographic variables and diagnoses was extracted. During the interview the information was recorded using the online database Parantion (Parantion Web Survey 6.8), patient data being anonymous.

Data processing

For the ICF components Body Functions, Body Structures and Activities and Participation absolute frequencies of impairments/limitations mentioned by the study population were reported. For Environmental Factors absolute frequencies of specific categories that were named to be a barrier or facilitator were reported. ICF categories that were not mentioned by at least 10% of the study population were considered not relevant, except for the midline lymphedema items, because this condition is relatively rare. Responses of patients with combinations of lymphedema locations were excluded from the analysis.

Results

Two hundred patients were included in the study. Patients' ages ranged from 22 to 84 years, with a mean age of 56. Most patients were female (87.5%). The mean duration of lymphedema was 11 years (range of 3 months to 77 years). There were 88 patients with upper limb lymphedema, 89 patients with lower limb lymphedema and eight patients with midline lymphedema (i.e. two patients with lymphedema of the thorax, one with lymphedema in the head and neck region and five patients with genital lymphedema). In addition, there were 15 patients with combinations of locations with lymphedema, who were excluded from the study. There were 142 outpatients and 58 inpatients (treated for lymphedema). In total 27% of patients had primary lymphedema. Twenty health professionals interviewed the 200 patients: 56 by physicians (28%), 71 by nurses (35%), 57 by physical therapists (29%), and 16 by skin therapists (8%). These professionals rated the patients' health with a mean of 4.2 and the magnitude of the problems in functioning of the patient in everyday life with 4.4 on a scale ranging from 0 (no problem) to 10 (complete problem). Patients themselves rated their health at a mean of 2.5 and 38% (76 patients) reported no problems in daily life (mean 4.6).

Tables II–V show the most mentioned ICF categories with impairments, limitations, barriers or facilitators for the four ICF components. The complete tables with all categories that were reported by at least 10% of the study sample are provided as Supplementary Tables I–IV to be found online at http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.1001873.

Body Functions

Most mentioned categories in Body Functions were for both the upper and lower limb affected patients: 'b710, Mobility of joint functions', 'b730, Muscle power functions', and 'b530, Weight maintenance functions'. For the midline location the most mentioned categories were: 'b152, Emotional functions', 'b126, Temperament and personality functions', and 'b640, Sexual functions'.

Body Structures

For the upper limb the most mentioned categories were: 's720, Structure of shoulder region', 's730, Structure of upper extremity', and 's810, Structure of areas of skin'. The most mentioned categories in the lower limb were: 's750, Structure of lower extremity', 's810, Structure of areas of skin', and 's740, Structure of pelvic region'. For midline lymphedema patients the following categories were the most important: 's810, Structure of areas of skin', 's720, Structure of shoulder region', and 's420, Structure of immune system'.

Activities and Participation

In this component the most mentioned items for the upper extremity were: 'd640, Doing housework', 'd445, Hand and arm use', and 'd430, Lifting and carrying objects'. For the lower limb these were: 'd415, Maintaining a body position', 'd450, Walking', and 'd410, Changing basic body position'. For midline patients the most important categories were: 'd640, Doing housework', in 'd410, Changing basic body position', and 'd920, Recreation and leisure'.

Environmental Factors

In this component there was a division in facilitators and barriers. The following categories for the upper

Table I. Characteristics of the patients.

Characteristic	Total (n = 185)	ULL (n = 88)	LLL (n = 89)	Midline (n = 8)
Mean age (range)	55 (22–83)	60 (23–83)	50 (22–78)	57 (42–72)
Female (%)	81%	98.9%	69.7%	12.5%
Duration lymphedema (years)	11.6	7.5	15.8	8.9
Employment (%)	44.8%	26.1%	60.7%	75%

LLL, lower limb lymphedema; ULL, upper limb lymphedema.

Table II. Most mentioned impairments in the component Body Functions.

ICF code	Description	0 = no impairment			1 = mild impairment			2 = moderate impairment			3 = severe impariment			4 = complete impairment			Total 8 + 9 + C		
Location lymphedema		U	L	M	U	L	M	U	L	M	U	L	M	U	L	M	U	L	M
b126	Temperament and personality functions	82	76	62	14	13	13	3	7	25	0	1	0	0	1	0	1	2	0
b152	Emotional functions	65	62	50	22	24	37.5	8	7	0	3	3	12.5	0	1	0	2	3	0
b530	Weight maintenance functions	51	64	75	35.5	26	25	10.5	9	0	2	1	0	0	0	0	1	0	0
b640	Sexual functions	72	79	50	8	10	12.5	0	4	0	1	0	12.5	2	0	12.5	17	7	12.5
b710	Mobility of joint functions	41	49.5	75	26.5	21.5	0	18.5	26	12.5	5	0	0	1	0	0	7	3	12.5
b730	Muscle power functions	43	58	75	24	25	12.5	20	14	0	5	2	0	0	0	0	7	1	12.5

N = 88 patients with lymphedema of the upper extremity (U; white colored columns), N = 89 patients with lymphedema of the lower extremity (L; yellow colored columns). N = 8 patients with midline lymphedema (M; blue colored columns). 8 = not specified; 9 = not applicable; C, comorbidity. The numbers for 8, 9 and C are added (Total 8,9,C).

extremity were most mentioned as facilitators: 'e355, Health professionals', 'e310, Immediate family', and 'e320, Friends'. Whereas 'e125, Products and technology for communication', 'e355, Health professionals', and 'e225, Climate' were seen as barriers. Facilitators for the lower limb were the same as for the upper limb. For the barriers there was a slight difference: 'e225, Climate', 'e460, Societal attitudes', and 'e355, Health professionals' were most mentioned. Most mentioned facilitators for the midline region were: 'e310, Immediate family', 'e355, Health professionals', and 'e580, Health services, systems and policies'. Barriers were: 'e225, Climate', 'e355, Health professionals', and 'e460, Societal attitudes'.

Table III. Most mentioned impairments in the component Body Structures.

ICF code	Description	0 = no impairment			1 = mild impairment			2 = moderate impairment			3 = severe impairment			4 = complete impairment			Total		
Location lymphedema		U	L	M	U	L	M	U	L	M	U	L	M	U	L	M	U	L	M
s420	Structure of immune system	88		87.5	6		12.5	5			1						0		0
s720	Structure of shoulder region	48		75	22		12.5	16		12.5	7			2			5		0
s730	Structure of upper extremity	56		87.5	18		12.5	15			8						3		0
s740	Structure of pelvic region		68			18			3									11	
s750	Structure of lower extremity		30.3			30.3			30.3			6.1			1			2	
s810	Structure of areas of skin	84	74	75	7	18	12.5	8	6		1	2	12.5				0	0	0

N = 88 patients with lymphedema of the upper extremity (U; white colored columns), N = 89 patients with lymphedema of the lower extremity (L; yellow colored columns). N = 8 patients with midline lymphedema (M; blue colored columns). 8 = not specified; 9 = not applicable; C, comorbidity. The numbers for 8, 9 and C are added (Total 8,9,C).

Discussion

In this cross-sectional study the most common problems of lymphedema patients were explored using the ICF. The findings of this research make clear that all four components of the ICF (Body Functions, Body Structures, Activities and Participation, and Environmental Factors) are relevant for patients with lymphedema.

In the component Body Functions, functions of joint mobility, muscle power, and weight maintenance were impaired most frequently for upper and lower extremity. A literature study about lymphedema-specific questionnaires presented impairments of

Table IV. Most mentioned limitations and restrictions in the component Activities and Participation.

ICF code	Description	0 = no limitation/ restriction			1 = mild limitation/ restriction			2 = moderate limitation/ restriction			3 = severe limitation/ restriction			4 = complete limitation/ restriction			Total 8 + 9 + C		
Location		U	L	M	U	L	M	U	L	M	U	L	M	U	L	M	U	L	M
d410	Changing basic body position	68	49.5	4	16	30.5	12.5	11	16	12.5		1	12.5				5	3	12.5
d415	Maintaining a body position	50	66.3	62.5	28	21.7		14	10	12.5	5					12.5	3	2	12.5
d430	Lifting and carrying objects	27	59	62.5	32	19		30	9	12.5	5		12.5	3			3	2	12.5
d445	Hand and arm use	26		87.5	32			24		12.5	14			1			3		0
d450	Walking	67	36	62.5	10	36		8	18	12.5		6	12.5	1			14	4	12.5
d640	Doing housework	24	64.3	50	35	27.7	12.5	30	4	37.5	10	1					1	3	0
d920	Recreation and leisure	61.3	57.3	5	17	22.4	2	12.7	13.4	1	5	4.5		2			2	2.4	0

N = 88 patients with lymphedema of the upper extremity (U; white colored columns), N = 89 patients with lymphedema of the lower extremity (L; yellow colored columns). N = 8 patients with midline lymphedema (M; blue colored columns). 8 = not specified; 9 = not applicable; C, comorbidity. The numbers for 8, 9 and C are added (Total 8,9,C).

the immunological system (swelling), pain and touch functions as most measured categories [8]. Furthermore, in another study using focus groups the most frequently mentioned categories were: immunological system functions, emotional functions (emotions such as fear, anger, joy); pain, temperament and personality functions (including psychic stability, confidence and optimism), and sensations related to the skin (including itching and tingling) [9]. The results of these two studies show a rather broad spectrum of impairments, but the findings of this study are slightly different with more attention to mobility and muscle strength. Weight maintenance is of great importance, because overweight is one of the risk factors for developing lymphedema. This is in line with previous studies [10,11]. In this study 74.5% of the patients considered pain as no problem and 78.9% had no problems concerning swelling. In the focus groups all patients mentioned pain and swelling as problems, whereas in the lymphedema-specific questionnaires 75% contained questions about pain and 83% about swelling. This could be related to the specific treatment the patients received with more focus on mobility and muscle strength and the fact that most of the patients were in the maintenance phase (when the lymphedema has stabilized), in which swelling was no limitation any more. In the maintenance phase the lymphedema already exists for a longer period. Since the mean duration of the lymphedema was 11.6 years (see Table I), it may be concluded that most of the patients were in this phase. In addition, midline patients have more problems mentally and with sexual functions. Although the patients with upper limb and lower limb lymphedema also mentioned problems with sexual functions (11.3% and 14.6%, respectively), it is quite understandable that patients with lymphedema in the genital region had more problems (37.5%), considering the impact of having lymphedema in that region.

Table V. Most mentioned barriers and facilitators in the component Environmental factors.

<table>
<tr><th>ICF code</th><th>Description</th><th colspan="3">0 = no barrier|facilitator</th><th colspan="3">1 = mild barrier|facilitator</th><th colspan="3">2 = moderate barrier|facilitator</th><th colspan="3">3 = severe barrier|facilitator</th><th colspan="3">4 = complete barrier|facilitator</th><th colspan="3">Total 8 + 9 + C</th></tr>
<tr><td>Location</td><td></td><td>U</td><td>L</td><td>M</td><td>U</td><td>L</td><td>M</td><td>U</td><td>L</td><td>M</td><td>U</td><td>L</td><td>M</td><td>U</td><td>L</td><td>M</td><td>U</td><td>L</td><td>M</td></tr>
<tr><td>e125</td><td>Products and technology for communication</td><td>65</td><td>80</td><td>50</td><td>2|10</td><td>2.2|3.3</td><td></td><td>5|6</td><td>0|3.5</td><td></td><td>0|2</td><td>1|2</td><td>0|12.5</td><td>0|1</td><td></td><td></td><td>9</td><td>8</td><td>37.5</td></tr>
<tr><td>e225</td><td>Climate</td><td>41</td><td>36</td><td>50</td><td>20.4|6.6</td><td>20|6</td><td>25|0</td><td>20|2</td><td>26|3</td><td></td><td>2|1</td><td>1|1</td><td></td><td></td><td>0|1</td><td>12.5|0</td><td>7</td><td>6</td><td>12.5</td></tr>
<tr><td>e310</td><td>Immediate family</td><td>32</td><td>39.3</td><td>25</td><td>5|19</td><td>2.2|20</td><td>0|25</td><td>2|23</td><td>2.2|23</td><td>0|25</td><td>2|14</td><td>0|10</td><td>12.5|12.5</td><td>0|2</td><td>0|2.2</td><td></td><td>1</td><td>1.1</td><td>0</td></tr>
<tr><td>e320</td><td>Friends</td><td>45</td><td>49.7</td><td>50</td><td>3|24</td><td>2.2|29.2</td><td>0|25</td><td>0|13</td><td>1.1|7.8</td><td></td><td>0|2</td><td>0|7.8</td><td>0|25</td><td>|2</td><td></td><td></td><td>0</td><td>2.2</td><td>0</td></tr>
<tr><td>e355</td><td>Health professionals</td><td>30</td><td>26</td><td>25</td><td>5|19.3</td><td>8|16</td><td>0|37.5</td><td>1.1|20.4</td><td>7|20</td><td>12.5|0</td><td>2.3|19</td><td>0|20</td><td>12.5|12.5</td><td>0|2</td><td>0|2</td><td></td><td>1</td><td>1</td><td>0</td></tr>
<tr><td>e460</td><td>Societal attitudes</td><td>76</td><td>74.2</td><td>62.5</td><td>7|9</td><td>12.4|3</td><td></td><td>2|5</td><td>6|1.1</td><td>0|12.5</td><td>1|0</td><td></td><td>25|0</td><td></td><td></td><td></td><td>0</td><td>3.4</td><td>0</td></tr>
<tr><td>e580</td><td>Health services, systems and policies</td><td>49.2</td><td>45</td><td>37.5</td><td>9.1|16</td><td>7|19</td><td>0|37.5</td><td>2.3|10</td><td>6|10</td><td>12.5|0</td><td>0|9</td><td>0|5</td><td></td><td>0|1</td><td>1|1</td><td>0|12.5</td><td>3.4</td><td>6</td><td>0</td></tr>
</table>

N = 88 patients with lymphedema of the upper extremity (U; white colored columns), N = 89 patients with lymphedema of the lower extremity (L; yellow colored columns). N = 8 patients with midline lymphedema (M; blue colored columns). 8 = not specified; 9 = not applicable; C, comorbidity. The numbers for 8, 9 and C are added (Total 8,9,C).

In the component Activities and Participation, most relevant categories pertained to recreation and leisure, doing housework and maintaining a body position. These are also the results of the focus group research [9], whereas in the literature review these items are less prominent [8]. In the lymphedema-specific questionnaires the most occurring item is 'looking after one's health'. In the focus group research, all patients mentioned problems with self-management, which is no or only a small problem (6.5%) for the patients of this study. Probably this is a result of the self-management training as part of the treatment policy of the participating hospital.

Family, health professionals and friends were perceived as facilitators for the upper and lower limb in the component Environmental Factors. For midline patients health services, systems and policies were also important facilitators. This emphasizes the importance of patients' social network and the influence of the health professionals. Although no discrimination was made between facilitators and barriers in the literature review as well as the qualitative review with focus groups, the same categories are important with one exception: 'Products and technology for personal use in daily living' was the most mentioned item in these studies [8,9]. This category contains items like bandaging and hosiery; which are important items for lymphedema patients. It remains unclear why these items play a less important role in this present study. Perhaps the patients in this study are more adapted to the use of these assistive products. Health professionals are also mentioned as important barrier. Patients describe the ignorance and play down of the health professionals when speaking of lymphedema during cancer treatment. In one of the interviews a patient gave an example of how the surgeon reacted, when she mentioned her problems with her swollen limb: "Why are you complaining about swelling in your arm? You are lucky to be alive." This is in line with the previous qualitative research. Consequently, there is a need for more education and a change in attitude concerning lymphedema among health professionals.

The participating health professionals rated the patients' health with a mean of 4.2 and the magnitude of the problems of the functioning of the patient with 4.4, whereas the patients themselves rated their health with 2.5 and the problems of their daily living with 2.4. It seems that the health professionals overrate the level of problems that patients experience. The data of the patients are not in line with the previous qualitative research. In the latter, patients experienced more problems than in this present research. This could be a result of the fact that in the focus groups the topics were discussed more profound and the rather small sample (n = 31).

This study has some potential weaknesses. All patients were recruited from one single hospital. This could serve as a bias, because of the policy of treatment of lymphedema (focus on self-management) brings forward special attitudes of health professionals and patients, which cannot be generalized for the whole population. However, this can be of advantage when patient groups from several institutes will be compared in future research; either from a therapeutic approach or demographic point of view. Furthermore, the recruitment was not performed at random or blinded. Although both limitations are obvious, the data of this study represent a considerable part of the distribution of problems in functioning of patients with lymphedema.

Conclusion

The purpose of this cross-sectional study was to provide data of patients with lymphedema as one of the preparatory studies for the development of ICF Core Sets for lymphedema. This resulted in a representation of the assessment of the patients' perspective by health professionals, using the ICF. The in-depth knowledge of the typical spectrum of problems encountered in lymphedema patients can contribute to the optimal management of lymphedema patients, the teaching of professionals, the planning of studies and the development of assessment instruments.

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Supplementary material available online

Supplementary Table I-IV to be found online at http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.1001873.