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RESEARCH PAPER

Broadening the scope on health problems among the chronically neurologically ill with the International Classification of Functioning (ICF)

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Abstract

Purpose. The aim of this study was to determine ICF items indicating health problems for patients with a chronic neurological disorder such as multiple sclerosis, Parkinson's disease and neuromuscular disease.

Method. A Delphi study using three disease-specific panels composed of patients and proxies, medical and non-medical health professionals ($N=98$). Panels were asked to select items from the International Classification of Functioning, Disability and Health (ICF) reflecting relevant disease-specific health problems. Items appraised as relevant by the panel members were compared with items in established measures namely: the Minimal Record of Disability (MRD) and the Disability and Impact Profile (DIP).

Results. Sixty-eight ICF items were considered to be the most relevant, and belonged to four ICF domains. No significant differences were found between the appraisal of items by patients/proxies and health professionals. Agreement across the disease panels appeared to be (very) strong. Differences between the three disease-specific panels were found for the 'Body Functions and Structures' domain: consensus was reached by extension of the inclusion criteria. The ICF-item selection covers almost all items of the established measures. The largest contrast was shown in the item selection for the 'participation' and 'environmental factors' domains.

Conclusions. Selected items indicate a broader scope in studying health problems compared with widely used health status measures in neurology, especially for the ICF domains 'Participation' and 'Environmental Factors'.

Keywords: ICF, International Classification of Functioning, disability and health, multiple sclerosis, Parkinson's disease, neuromuscular diseases, rehabilitation

Introduction

The definitive diagnosis of a chronic neurological disease such as multiple sclerosis, Parkinson's disease or a neuromuscular disease has enormous consequences on the health status and everyday functioning of a person, such as performance of tasks, participation in social life, housing, work and income. Over the last two decades many health measures have been developed and used in both clinical practice and research. Some instruments are measures used among patient groups with a different chronic disease,

for example the Disability and Impact Profile (DIP) [1,2] applied in rehabilitation medicine; some measures are disease-specific, such as the Minimal Record of Disability (MRD) [3] for Multiple Sclerosis; others are one-dimensional and purely function-oriented such as the Barthel index [4], or have a multidimensional structure covering 'physical functioning', 'psychological functioning' and 'social functioning', like Quality of Life instruments such as the 36-item Short Form Health Survey Questionnaire (SF-36) [5], the 54-item Multiple Sclerosis Quality of Life Scale (MSQoL-54) [6] or the 59-item

Functional Assessment of Multiple Sclerosis Quality of Life Questionnaire (FAMS-59) [7]. Due to the prolific development and use of health measures there are now ‘competing’ instruments in the area of neurology demonstrating significant differences in the contents of important domains of health-related functioning. Moreover, there is no consensus on how to measure these domains [8]. Furthermore, comparisons across chronic diseases are problematic. Consequently, it seems necessary to develop an internationally accepted frame of reference in order to define functioning, disability and health [8,9].

The International Classification of Function, Disability and Health (ICF) of the World Health Organization (WHO) [10] systematically describes consequences of disease on functioning and health. This classification covers almost all aspects of health, which are systematically grouped in domains related to ‘body functions and body structures’ (Body Functions and Structures domain), ‘performance of tasks’ (Activities domain), ‘involvement in life situations’ (Participation domain) as well as ‘factors with an impact on all domains of functioning’ (Environmental Factors). ICF-based measures may provide support to overcome these comparison problems. With about 1500 categories in its original form the ICF is hardly practical and lacks feasibility. Therefore, Stucki et al. [9,11] suggest defining short lists, so-called Core Sets, of categories which are relevant for specific conditions (e.g., stroke) or health care situations (e.g., sub-acute care).

The main purposes of this study were (1) from the complete set of ICF-items to select a representative sample of health-related aspects appraised as relevant and appropriate for patients with multiple sclerosis (MS), Parkinson’s disease (PD) and neuromuscular diseases (NMD) such as motor neuron diseases and muscular dystrophies, and (2) to give an indication of the content validity of the final set of included items.

Methods

At the start of the study it was obvious that a large sample of experts would be needed to achieve consensus on the (clinical) relevance of the final set of selected items derived from the complete set of ICF items. The (written) Delphi technique was used since it is an efficient means of combining the expertise of a large, geographically dispersed group of experts [12]. Experts were asked to complete two assessment questionnaires. No face-to-face discussions took place.

Panels

We organized the item selection among independent panels for each of the diseases separately since it was

not clear whether significant differences would occur in the selection of items between these diseases:

1. The multiple sclerosis subpanel.
2. The Parkinson’s disease subpanel.
3. The neuromuscular diseases subpanel.

Since we consider patients to be experts, at least one-third of each disease subpanel should consist of patients or proxies. Two-thirds of each subpanel should consist of health professionals representing relevant medical and non-medical disciplines. Consequently, a large proportionate stratified sample consisting of three strata was used:

1. Patients and proxies.
2. Medical professionals: neurologists, rehabilitation specialists, general practitioners, nursing home doctors and nurse practitioners.
3. Non-medical health professionals: nurses and nurse specialists, physiotherapists, occupational therapists and social workers.

Patients and proxies were recruited among members of the local and national patient associations. It was assumed that their response reflected the association’s collective framework of reference in order to avoid information bias. Professionals were recruited on the basis of their disease-specific expertise from well-known specialized centres for neurological diseases in The Netherlands and Belgium.

Potential panel members were approached by means of a letter containing information about the goals, methods and estimated required participation time, followed by a telephone call in order to answer any questions. After informed consent was received, the questionnaire for the first assessment was then mailed.

Item selection

According to the ICF, items belonging to the following categories were assessed by panel experts:

1. Body Functions and Structures: aspects of body functions and body structure.
2. Activities: activities at the individual level.
3. Participation: aspects of participation in society.
4. Environmental Factors: contextual aspects with impact on the other three domains.

No item preselection was made to avoid selection bias. Consequently, at baseline the experts in the panels had to appraise each item from the complete set of ICF items. The response options ranged from ‘not relevant’ (score 0), to ‘very relevant’ (score 4). If panel members could not make up their minds

about an assessment, they could answer with a question mark. Respondents were instructed to fill out the questionnaire with time intervals in order to reduce bias through attrition and to optimise the respondents' compliance [12]. Body Functions and Structures domain items were appraised only by the 'medical professionals' since assessment of these items requires specific medical expertise.

Ordinal data was elaborated in order to detect skewed distributions, outliers and items with extreme outcomes on the central tendency measures. Criteria [12] for inclusion of an ICF item in the initial sample were:

1. An item appraised as 'very relevant' (median = score 4) by at least one disease subpanel.
2. An item appraised as 'very relevant' by the stratum comprising 'patients and proxies' (median = score 4).

Although ICF items appraised by the complete panel as 'relevant' (median = score 3) were valued as less important, they were included in the initial sample in order to test whether this criterion might lead to erroneous item selection.

Items included in these initial samples of 'very relevant' and 'relevant' items were presented to the disease panels in the second assessment with the request to 'agree' to include the items in the sample of 'very relevant' items in the final item selection, or to 'agree' with final rejection of items included in the sample of 'relevant' items. The criterion for inclusion of an item in the final selection was a score of 0.80 on the content validity index [12], indicating a good content validity across the expert ratings of each item's relevance: at least 80% of the complete panel had to agree with an item's inclusion in the item sample. In cases where 80% of the experts agreed on inclusion of an item in only one or two subpanels, while in the overall sample less than 80% agreed on inclusion, the investigators decided on final inclusion.

Interrater agreement

Although a general consensus was obtained in the second assessment according to the inclusion criteria, the assessment procedure did not allow the calculation of obvious measures of interrater reliability such as Cohen's κ [13].

Therefore, we suggest the interrater agreement index D as a measure of dispersion, expressing the mean of the absolute values of the deviations from the median as follows:

$$D = \frac{\sum_{i=1}^n |(X_i - M)|}{N}$$

where X_i is the expert rating; N is the number of experts; and M is the median.

The value by which we express the agreement index (D) across the expert rating of each item's relevance has the advantage of easy interpretation. In the current study, the ordinal scales have a range from 0 to 4. A minimum D value of zero indicates that the experts unanimously appraise an item as relevant (each expert's score = 3; median = 3) or very relevant (each expert's score = 4; median = 4). When the sample of experts is not unanimously in agreement with the appraisal of an item's relevance, the value of D is above zero. The maximum D value only occurs in the unlikely situation that the appraisal score of an item's relevance is the extreme opposite of the median. Since the sample of experts in the current study was homogeneous, it seems reasonable to expect a level of agreement between 0 and 1.

Convergent validity

To evaluate the content validity of the final sample of items the selected items were compared with the contents of two well-known valid and reliable measures: a disease-specific and a generic quality of life measure. The items of these measures were linked to the selected ICF items by two independent health professionals with expertise in health-related functional status measures as well as in both the ICF content and neurological diseases. Experts were asked to link each item belonging to the final sample meticulously to the content of the corresponding ICF item. Consensus on matched pairs of items between the two health professionals was used to decide to which ICF item the sample items should be linked. To resolve disagreements between the two health professionals, a third independent person with the same expertise was consulted [14].

We used the Minimal Record of Disability (MRD) for the disease-specific evaluation [3,15], also known as the Minimal Data Set for Multiple Sclerosis. The MRD is based on the first version of the ICF, namely the 'International Classification of Impairments, Disabilities and Handicaps' (ICIDH) [16–18]. The MRD is based on three main domains:

1. The Impairment domain is reflected in the observation based Functional Systems (FS) scale and the overall Expanded Disability Status Scale (E)DSS [19].
2. The Disabilities domain is reflected in the self-report Incapacity Status Scale (ISS) [20,21].
3. The Handicaps domain is reflected in the self-report Environmental Status Scale (ESS) [22].

The subscales of the MRD are widely used in both research and clinical practice and have satisfactory psychometric properties [23–33].

The Disability and Impact Profile (DIP) [1,2,34] was used for the generic quality of life evaluation in rehabilitation. It is a self-report screening instrument to assess disabilities, individually weighted with respect to their relative importance or impact as perceived by the rehabilitee. Although it has been developed as a clinical instrument for the identification of needs of individual patients, it is also used as a population-specific rehabilitation Quality of Life measurement. The DIP contains symptom questions and questions in five areas: mobility, self-care, communication, social activities and psychological status.

Results

Panel member characteristics

A total of 98 experts participated in the study: 37 were patients and proxies (38%) and 61 were health professionals (62%) (Table I). The multiple sclerosis subpanel included 42 respondents, 19 of whom were patients and proxies (45%), and 23 health professionals (55%). The Parkinson's disease subpanel comprised 31 respondents, nine of whom were patients and proxies (29%), and 22 health professionals

(71%). The neuromuscular diseases sub-panel consisted of 25 respondents, nine of whom were patients or proxies (36%) and 16 health professionals (64%).

The proportion of patients and proxies was disproportionately distributed across the disease panels with 51% in the Multiple Sclerosis panel. However, the differences in the proportions of patients and proxies between the disease panels were not statistically significant (MS vs. PD = 16.2%; 95% CI: –5.7–38%, MS vs. NMD = 9.2%; 95% CI: –15.2–33% and PD vs. NMD = 7.0%; 95% CI: –32–18%). Furthermore, no statistically significant differences in proportions between the strata of medical and non-medical experts were found across the disease-specific panels.

Item sampling

First assessment results: No significant differences were found between the strata 'patients and proxies' and 'health professionals', or between the disease subpanels of experts with regard to the sample result of items belonging to the ICF domains 'Activities', 'Participation' and 'Environmental Factors'. In accordance with the inclusion criteria, the resulting item samples were merged into one sample comprising 46 'very relevant' and 96 'relevant' items which were then submitted in the second assessment.

Table I. Expert characteristics across panels ($n = 98$).

	MS panel	PD panel	NMD panel	Overall panel
Patients and proxies				
Patients	17	7	7	31
Proxies	2	2	2	6
Subtotal	19 (51.4) (45.2)	9 (24.3) (29.0)	9 (24.3) (36.0)	37 (100) (37.8)
Medical experts				
Nurse Practitioners	1	1	1	3
Rehabilitation doctors	4	2	2	8
Neurologists	5	4	4	13
General Practitioners	–	1	–	1
Nursing home doctors	1	1	–	2
Subtotal	11 (40.7) (26.2)	9 (33.3) (29.0)	7 (25.9) (28.0)	27 (100) (27.6)
Non-medical experts				
Nurses and Nurse specialists	6	6	4	16
Physiotherapists	3	3	2	8
Occupational therapists	2	2	1	5
Welfare workers	1	2	2	5
Subtotal	12 (35.3) (28.6)	13 (38.2) (41.9)	9 (26.5) (36.0)	34 (100) (34.7)
Total	42 (42.9) (100)	31 (31.6) (100)	25 (25.5) (100)	98 (100) (100)

Italic percentages across columns.

Bold percentages across rows.

The selection of ICF items from the 'Body Functions and Structures' domain showed significant differences between the disease subpanels. According to the inclusion criteria for the initial sample, the number of body functions items as well as the content of selected items differed, with Multiple Sclerosis having 39 items, Parkinson's disease 29 items and neuromuscular diseases 28 items. It was therefore decided not to merge the 'Body Function and Structures' item samples from the disease subpanels. Each subpanel was requested to appraise the disease-specific outcome of the first assessment for this domain within the second assessment.

Second assessment results: According to the criterion of the content validity index, at least 80% of the complete panel had to agree with the inclusion of an item in the domains 'Activities', 'Participation' and 'Environmental Factors'. Two items were therefore removed from the first selection of 'very relevant' items, and two items from the selection of 'relevant' items were added to the 'very relevant' items. For the 'Body Functions and Structures' domain the criteria for selection were broadened in order to achieve consensus on a representative sample of items: an item was selected in the final sample when 80% agreed with inclusion of an item in one or more subpanels rather than in each of the three subpanels.

Finally, 68 'very relevant' items, belonging to the four domains of the ICF, were selected: Body Functions and Structures (20 items); Activities (21 items), Participation (17 items) and Environmental Factors (10 items).

Interrater agreement

The agreement indexes (*D*) for the final selected items were calculated. The results in Table II show a large amount of agreement (range between 0 and +1) across the disease subpanels and in the overall panel.

Convergent validity

The 31 items belonging to the MRD and the 40 items belonging to the DIP were linked to the selected ICF items as shown in Tables III–VI. Generally, one item from the convergent measure was linked to one item of the ICF selection, indicated by a '1' in the table. A higher number in the table indicates that an item of the health status measure addressed the same ICF item, or that the selected ICF item did not differentiate in greater detail, and therefore several items from the measure had to be linked to the same ICF item. For example the MRD items 'Cerebral (or) mental functions' (FS 7), 'Mentation' (ISS 13) and 'Mood and Thought' (ISS 14) had to be linked to the same ICF item

'Thought functions' (b160). Newly selected ICF items by the panel that were not addressed by the measure's items are indicated by a dash (–) in the tables.

Disease-specific convergent validity: The ICF item selection includes almost all items belonging to the disease-specific measure for Multiple Sclerosis, the MRD, except for three not definable items: 'Hearing', 'Stair climbing' and 'Medical problems'. However, 27 items are newly selected in this study in comparison to the MRD items, as shown in Tables III–VI. The panel selected the items 'Sleep functions', 'Attention functions', and 'Exercise tolerance' belonging to the 'Body Functions and Structures domain'. Eight new items were selected comprising the 'Activities' domain concerning 'communication' (two items), 'mobility' (two items), 'self care' (two items) and 'domestic life' (two items). The greatest contrast was reflected by the results of the item selection regarding the 'Participation' and 'Environmental Factors' domains: all MRD items are covered by the sample of ICF items, but the ICF panel selected 16 items that do not belong to the MRD. For the participation domain these items concerned participation in 'communication' (two items), 'mobility' (two items), 'self care' (five items) and 'domestic life' (one item). Items selected from the Environmental Factors domain concerned 'products and technology' (four items), 'support and relationships' (one item) and 'services, systems and policies' (one item).

Generic convergent validity: The ICF item selection covers almost all items of the DIP except for six not definable items concerning 'visible deformities', 'stand', 'climb stairs', 'hear', 'determine day program' and 'reach goal in life'. Thirty-two items have been newly selected in this study. The panel selected five items for 'muscle and movement functions' for the 'Body Functions and Structures' domain. The panel selected seven more items for the 'Activities' domain concerning 'communication' (two items), 'mobility' and 'self care' (three items). The largest contrast was shown in the item selection for the 'Participation' and 'Environmental Factors' domains: all items in the DIP are covered, but the panel selected 18 items which do not appear in the DIP. These concerned items about participation in 'communication' (two items), 'mobility' (one item), 'self-care' (five items) and 'community' (one item) and all 10 selected items in the 'Environmental Factors' domain with the exception of the 'social security services' item.

Discussion

The main challenge in this study was to develop a comprehensive yet concise set of items covering the

Table II. Median scores on item relevance and the interrater agreement index (*D*) for the final selected ICF items within the disease sub-panels and overall panel.

	Multiple sclerosis sub-panel		Parkinson's disease sub-panel		Neuromuscular disease sub-panel		Overall panel	
	Median	<i>D</i>	Median	<i>D</i>	Median	<i>D</i>	Median	<i>D</i>
Body functions								
Energy level	4	0.21	4	0.50	4	0.67	4	0.44
Sleep functions	3	0.40	4	0.34	3	0.87	3	0.53
Attention functions	3	0.78	3	0.60	3	0.79	3	0.70
Memory functions	3	0.60	3	0.90	3	0.85	3	0.78
Emotional functions	4	0.50	3	0.78	4	0.67	4	0.66
Thought functions	3	0.90	4	0.40	3	0.83	3	0.73
Seeing functions	4	0.50	3	0.70	3	0.55	3	0.59
Sensation of pain	4	0.40	4	0.70	4	0.25	4	0.41
Articulation functions	4	0.20	3	0.75	3	0.89	3	0.63
Exercise tolerance	4	0.40	4	0.30	4	0.27	4	0.31
Swallowing	3	0.55	3	0.20	3	0.36	3	0.37
Defecation functions	4	0.30	3	0.80	3	0.78	3	0.63
Urinary functions	4	0.20	3	0.77	4	0.58	3	0.51
Muscle power functions	4	0.50	4	0.40	4	0.23	4	0.39
Control of voluntary movements	4	0.50	4	0.60	4	0.41	4	0.52
Involuntary movements	4	0.40	4	0.20	3	0.38	3	0.31
Gait pattern functions	4	0.60	4	0.50	3	0.88	3	0.64
Sensations related to muscle and movements	3	0.71	4	0.47	4	0.25	3	0.45
Activities								
Speaking	3	0.90	3	0.83	3	0.95	3	0.89
Conversation	3	0.82	4	0.59	3	0.81	3	0.82
Using communication devices	3	0.62	3	0.67	3	0.74	3	0.67
Maintaining a body position	4	0.57	4	0.50	4	0.64	4	0.61
Changing basic body position	4	0.61	4	0.47	4	0.77	4	0.63
Transferring oneself	4	0.45	4	0.37	4	0.71	4	0.48
Fine hand use	4	0.65	4	0.43	4	0.50	4	0.54
Hand and arm use	4	0.55	3	0.53	4	0.77	4	0.61
Walking	4	0.45	4	0.10	4	0.50	4	0.35
Moving around using equipment	4	0.55	3	0.76	4	0.14	4	0.54
Using transportation as a passenger	4	0.54	4	0.82	3	0.86	4	0.73
Washing and drying oneself	4	0.45	4	0.37	4	0.38	4	0.40
Caring for body parts	4	0.50	4	0.30	4	0.54	4	0.44
Toiletting	4	0.35	4	0.37	4	0.40	4	0.36
Dressing	4	0.40	4	0.57	4	0.68	4	0.55
Eating	4	0.57	4	0.37	4	0.68	4	0.53
Drinking	4	0.65	4	0.40	4	0.45	4	0.52
Looking after one's health	3	0.85	4	0.50	4	0.81	4	0.75
Preparing meals	3	0.70	3	0.73	3	0.57	3	0.68
Doing housework	3	0.87	3	0.73	3	0.77	3	0.80
Engaging in physical intimacy	3	0.82	3	0.65	3	0.77	3	0.75
Recreation and leisure	3	0.66	3	0.57	3	0.64	3	0.62
Participation								
In personal care	4	0.32	4	0.42	4	0.71	4	0.45
In preparing meals	3	0.74	4	0.54	3	0.79	3	0.74
In mobility within the home	4	0.59	4	0.61	3	0.79	4	0.71
In mobility within buildings other than the home	4	0.19	4	0.19	4	0.33	4	0.23
In mobility outside the home and other buildings	4	0.31	4	0.29	4	0.54	4	0.36
In using transportation	4	0.31	4	0.33	4	0.37	4	0.33
In conversation	4	0.36	4	0.45	4	0.25	4	0.36
In using communication devices	4	0.53	4	0.54	3	0.75	4	0.46
In family relationships	4	0.32	3	0.40	4	0.67	3	0.41
In intimate relationships	4	0.47	4	0.58	4	0.91	4	0.61
In informal social relationships	4	0.36	4	0.45	3	0.86	4	0.50
In acquiring a place to live	3	0.64	3	0.45	3	0.62	3	0.57
In remunerative employment	4	0.48	3	0.42	4	0.87	3	0.67
In community life	4	0.66	3	0.79	4	0.83	3	0.81
In recreation and leisure	4	0.62	4	0.61	3	0.65	4	0.65

(continued)

Table II. (Continued).

	Multiple sclerosis sub-panel		Parkinson's disease sub-panel		Neuromuscular disease sub-panel		Overall panel	
	Median	D	Median	D	Median	D	Median	D
External factors								
Prod. and techn. for personal use in daily living	4	0.51	4	0.67	4	0.82	4	0.64
Prod. and techn. for communication	4	0.67	3	0.68	4	0.56	3	0.72
Prod. and techn. for mobility and transportation	4	0.25	4	0.64	4	0.26	4	0.38
Immediate family	4	0.42	4	0.48	4	0.58	4	0.48
Personal care providers and personal assistants	3	0.65	3	0.83	4	0.73	3	0.76
Transportation services	4	0.57	3	0.96	3	0.75	3	0.78
Social security services	4	0.33	4	0.74	4	0.61	4	0.52
Social security policies	4	0.64	4	0.64	4	0.54	4	0.61
Health services, systems and policies	4	0.38	4	0.35	4	0.21	4	0.32

D, index for interrater agreement: mean deviation from the median.

Table III. The number of items belonging to the ICF domain 'Body functions and structures' associated with MRD and DIP items.

ICF code	ICF label	MRD	DIP
	<i>Mental functions</i>		
B1300	Energy level	1	1
B134	Sleep functions	-	1
B140	Attention functions	-	1
B144	Memory functions	2	1
B152	Emotional functions	3	2
B160	Thought functions	3	-
	<i>Sensory functions and pain</i>		
B210	Seeing functions	3	2
B280	Sensation of pain	1	1
	<i>Voice and speech functions</i>		
B320	Articulation functions	2	1
	<i>Functions of cardiovascular and respiratory systems</i>		
B455	Exercise tolerance functions	-	1
	<i>Ingestion functions</i>		
B5105	Swallowing	1	-
B525	Defecation functions	2	1
	<i>Genitourinary and reproductive functions</i>		
B620	Urination functions	2	1
B640	Sexual functions	1	1
	<i>Muscle and movement functions</i>		
B730	Muscle power functions	1	1
B735	Muscle tone functions	2	-
B760	Control of voluntary movement functions	1	-
B765	Involuntary movements functions	1	-
B770	Gait pattern functions	4	-
B780	Sensations related to muscle and movement functions	1	-

wide spectrum of health problems for people with Multiple Sclerosis, Parkinson's disease and neuromuscular diseases. A Delphi study performed by 98 experts resulted in a representative sample of

Table IV. The number of items belonging to the ICF domain 'Activities' associated with MRD and DIP items.

ICF code	ICF label	MRD	DIP
	<i>Communication</i>		
A330	Speaking	1	1
A350	Conversation	-	-
A360	Using communication devices and techniques	-	-
	<i>Mobility</i>		
A410	Changing basic body position	1	1
A415	Maintaining a body position	1	-
A420	Transferring oneself	1	1
A440	Fine hand use	-	1
A445	Hand and arm use	-	2
A450	Walking	1	1
A465	Moving around using equipment	1	-
A470	Using transportation	1	1
	<i>Self-care</i>		
A510	Washing oneself	1	1
A520	Caring for body parts	1	-
A530	Toileting	2	1
A540	Dressing	1	1
A550	Eating	1	1
A560	Drinking	-	-
A570	Looking after ones health	-	-
	<i>Domestic life</i>		
A630	Preparing meals	-	1
A640	Doing housework	-	1
	<i>Community, social and civic life</i>		
A920	Recreation and leisure	1	1

68 clinically relevant items for these groups of chronically ill persons selected from the four ICF domains.

The study was explicitly aimed at including the experience of patients and proxies, but also from different professions contributing to a patient-centred item selection. This is why 38% of the panel members were patients or proxies and the other 62%

Table V. The number of items belonging to the ICF domain 'Participation' associated with MRD and DIP items.

ICF code	ICF label	MRD	DIP
	<i>Communication</i>		
P350	Conversation	–	–
P360	Using communication devices and techniques	–	–
	<i>Mobility</i>		
P460	Moving around in different locations	–	–
P470	Using transportation	–	1
	<i>Self-care</i>		
P510	Washing oneself	–	–
P520	Caring for body parts	–	–
P530	Toileting	–	–
P540	Dressing	–	–
P570	Looking after one's health	–	–
	<i>Domestic life</i>		
P610	Acquiring a place to live	1	1
P630	Preparing meals	–	1
	<i>Interpersonal interactions and relationships</i>		
P750	Informal social relationships	1	1
P760	Family relationships	1	1
P770	Intimate relationships	1	1
	<i>Major life areas</i>		
P850	Remunerative employment	1	1
	<i>Community, social and civic life</i>		
P910	Community life	2	–
P920	Recreation and leisure	1	1

Table VI. The number of items belonging to the ICF domain 'Environmental factors' associated with MRD and DIP items.

ICF code	ICF label	MRD	DIP
	<i>Products and technology</i>		
E115	Products and technology for personal use in daily living	–	–
E120	Products and technology for indoor and outdoor mobility and transportation	–	–
E125	Products and technology for communication	–	–
E155	Design, construction and building products and technology of buildings for private use	–	–
	<i>Support and relationships</i>		
E310	Immediate family	–	–
E340	Personal care providers and personal assistants	2	–
	<i>Services, systems and policies</i>		
E5400	Transportation services	–	–
E5700	Social security services	1	1
E5702	Social security policies	1	–
E580	Health services, systems and policies	1	–

consisted of health professionals from medical and non-medical health disciplines.

Analyses did not show any significant differences between the 'patients and proxies' and both 'health

professionals' strata. This may indicate that health-care professionals have a valid and accurate view of the consequences of neurological diseases within all ICF domains. It may also indicate that patients judged the relevance of items with a generic view beyond their personal situation.

A positive conclusion could be drawn about the evaluation of the disease-specific and the generic convergent validity of the final ICF item set. It became clear that almost all items, except for three items in the MRD and six items in the DIP, were covered by the selected ICF items while 27, respectively, 32 items were added with the ICF selection. The greatest contrast with these measures was found for the 'Participation' and 'Environmental Factors' domains. Applying this broader item selection to clinical practice and research might generate useful information.

The Delphi method, as applied in this study, proved to be a reliable way to select items from a large sample. Because we used questionnaires, it was possible to invite a broad and varied panel of experts from The Netherlands and Belgium to participate. Panel members did not need to travel and could answer the questions at any chosen moment. Although participation in the panel required substantial input by panel members, the drop out during the research was low and commitment was high. Another advantage of this written method is that information bias may have been avoided since persuasive or prestigious experts cannot have had an undue influence on the opinions of others, as could happen in a face-to-face situation during, for example consensus conferences [12]. The interrater agreement index *D* was developed in order to confirm the results from the content validity index. This new index provided a more accurate picture of the amount of consensus in the disease subpanels and in the overall panel. According to Raine et al. [35] we included this index of the strength of support and extent of agreement about each recommendation.

Merging items for the three disease subpanels caused no problem for the ICF domains 'Activities', 'Participation' and 'Environmental Factors'. This supported the assumption that consequences of chronic neurological diseases are similar, despite the differences in impairments caused by the disease. The consensus between the subpanels about the 'Body Functions and Structures' items, however, was more complicated. This finding supports the suggestion that disease-specific applications in the measurement of the body impairment items are indicated.

The ICF proved to be a useful classification for selecting items. No items were missed, although some panel members mentioned missing terms to cover patients' experiences and coping styles. Although the ICF language was experienced as formal

and sometimes difficult to understand, it turned out to be useful in an interdisciplinary setting: no misunderstanding of items arose.

The full version of the ICF with items on the third and fourth more detailed levels was initially presented to the panel in order to avoid selection bias. During the Delphi study, the decision was made to include items in the selection only at the third level of detail to reduce the number of selected items to a manageable number. This was assumed to be a safe decision for two reasons: (1) the goal of this study was to select items indicating problem areas, so detailed information was less relevant, and (2) for all issues except two the subpanels selected items on the third as well as the fourth level of detail, so no relevant items were excluded by this decision. Van Achterberg et al. [36] and Sykes et al. [37] also found a substantial preference for using items of the third level of detail in assessment tools. In a future item selection study with the same goal, it might be advisable to present only items from the third level of detail.

Compared with the substantial contribution and meaningful outcomes of the ICF Core Sets project [11] this study differed at three points. Firstly, patients and proxies were given a significant role in the item selection process, where the ICF Core Sets project needs a separate procedure for validating the ICF Core Set with patients [38]. Secondly, the application of Consensus Conferences in the ICF Core Sets project has the disadvantage of a risk of 'any one persuasive or prestigious expert having an undue influence on the opinions of others' [12]. In this study a written Delphi method was applied so each panel member was on equal footing with all others. Thirdly, in contrast with the procedures of the ICF Core Sets project, no literature review was performed to make a selection of items. A literature review was considered but not performed to avoid selection bias and to give each item an equal chance to be selected.

This study has some potential limitations. One limitation relates to the selection of experts. All experts came from The Netherlands and Belgium so results obtained in this study cannot be generalized to other countries without validation studies in other regions.

This study was conducted during the ICIDH-ICF revision process. In the first phase of the study the 'ICIDH-2 beta-2 draft' [39] was the most recent version of the Classification and was therefore used. The final draft was released in May 2001 and named 'International Classification of Functioning, Disability and Health' [10]. After finishing this study we decided to recode the selected ICIDH-2 items and codes into the new ICF items and codes. Each ICIDH-2 item was linked to a corresponding ICF item. An important change in the ICF is the integration of the 'Activities' and 'Participation'

domains into a single list. In this study the distinction between 'Activities' and 'Participation' was maintained with respect to the selection made by the panel. Although the recoding procedure was carried out meticulously by three independent experts on the ICIDH-2 and ICF, in the case we used the same set of items in the ICF structure and the wording of the experts' appraisal may have deviated from the outcomes of the current study.

In conclusion, selected items for persons with a chronic neurological disease covered a broader scope of health problems compared with existing instruments, especially for the 'Participation' and 'Environmental Factors' domains. The scope of research and clinical practice for chronic neurological disorders should be widened.

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