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Research Report

Content validity of the Comprehensive ICF Core Set for multiple sclerosis from the perspective of speech and language therapists

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Abstract

Background: The Comprehensive International Classification of Functioning, Disability and Health (ICF) Core Set for Multiple Sclerosis (MS) is a comprehensive framework to structure the information obtained in multidisciplinary clinical settings according to the biopsychosocial perspective of the International Classification of Functioning, Disability and Health (ICF) and to guide the treatment and rehabilitation process accordingly. It is now undergoing validation from the user perspective for which it has been developed in the first place.
Aims: To validate the content of the Comprehensive ICF Core Set for MS from the perspective of speech and language therapists (SLTs) involved in the treatment of persons with MS (PwMS).
Methods & Procedures: Within a three-round e-mail-based Delphi Study 34 SLTs were asked about PwMS' problems, resources and aspects of the environment treated by SLTs. Responses were linked to ICF categories. Identified ICF categories were compared with those included in the Comprehensive ICF Core Set for MS to examine its content validity.
Outcomes & Results: Thirty-four SLTs named 524 problems and resources, as well as aspects of environment. Statements were linked to 129 ICF categories (60 *Body-functions* categories, two *Body-structures* categories, 42 *Activities-&-participation* categories, and 25 *Environmental-factors* categories). SLTs confirmed 46 categories in the Comprehensive ICF Core Set. Twenty-one ICF categories were identified as not-yet-included categories.
Conclusions & Implications: This study contributes to the content validity of the Comprehensive ICF Core Set for MS from the perspective of SLTs. Study participants agreed on a few not-yet-included categories that should be further discussed for inclusion in a revised version of the Comprehensive ICF Core Set to strengthen SLTs' perspective in PwMS' neurorehabilitation.

Keywords: International Classification of Functioning, Disability and Health, ICF Core Set, multiple sclerosis, speech disorders, neurorehabilitation.

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What is already known on this subject?
The Comprehensive ICF Core Set for MS serves as a pool of categories to describe functioning in settings in which a comprehensive description and assessment of functioning is necessary. Up to now, validation studies of this Core Set using the Delphi method were carried out including physicians, physical and occupational therapists. This is the first validation study on the Comprehensive ICF Core Set for MS taking into account the perspective of SLTs experienced in the treatment of persons with MS.

What this paper adds?
The results of this study indicate that several ICF categories referring to communication problems, as well as cognitive and swallowing functions, are not yet included in the Comprehensive ICF Core Set for MS. When applying the Comprehensive ICF Core Set for MS in clinical work it is recommended additionally to include these aspects in the assessment and documentation to strengthen the needs of SLTs in this field.

Introduction

Limitations in communication associated with speech disorders or impairments in cognition and limitations in eating associated with impairments in swallowing are frequent in persons with multiple sclerosis (MS) (PwMS) (Hartelius *et al.* 2000). Approximately 50% of the persons with this neurodegenerative disease suffer from problems in communication (Murdoch and Theodoros 2000) and one-third have swallowing disorders (Poorjavad *et al.* 2010). Communication is fundamental to human life and eating is a vital function also strongly associated with human social interaction. Thus, both are strongly associated with quality of life (Klugman and Ross 2002), communicative participation (Baylor *et al.* 2011), and participation in general (Bringfelt *et al.* 2006). Even the smallest communication disorder can seriously impact the extent to which an individual achieves her or his occupational, personal and interpersonal goals (Murdoch and Theodoros 2000).

Treatment and rehabilitation of communication and swallowing are essential in rehabilitation of PwMS and require an inter-professional approach involving different health professionals, e.g. speech and language therapists (SLTs), physicians and (neuro)psychologists. SLTs as part of the inter-professional team address these impairments and limitations (Mackenzie and Green 2009) and are of outstanding importance for the rehabilitation of swallowing impairments, communication limitations and restrictions in participation of PwMS. The optimal management of MS in neurorehabilitation is based on an in-depth understanding and systematic consideration of the functioning and disability in PwMS (Stucki *et al.* 2003). This understanding of rehabilitation is represented by the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) (WHO 2001).

The ICF provides a unified language for the description of functioning and disability which are modified by contextual factors such as environmental and personal factors (WHO 2001). In line with this conceptualization the ICF classification is structured into the components *Body Functions* (designed with the letter b), *Body Structures* (s), *Activities & Participation* (d) and *Environmental Factors* (e), as well as *Personal Factors* which is not yet classified as the others components. The letters of the components are followed by one digit representing the chapter number followed by the second level (two digits) and the third and fourth levels (one digit each) to constitute the ICF categories (figure 1). The categories are hierarchically arranged in a structure that can be compared with a stem–branch–leaf scheme. Consequently, a higher level (more detailed) category (e.g. b5105 Swallowing) shares the lower level category (e.g. b510 Ingestion functions) of which it is the member. That means the use of a higher-level category implies that the lower-level category is applicable, but not vice versa.

Although different health professionals have their own core domains of interventions, a common framework is helpful to communicate about impaired body functions, limited activities and restricted participation of PwMS, rehabilitation goals and interventions applied. The ICF that represents such a framework is being increasingly taken into account by health professionals involved in inter-professional settings (Stucki *et al.* 2003). In line with this, clinical work of SLTs is increasingly influenced by the ICF and its biopsychosocial model of functioning and disability (Threats 2008, Walsh 2011). During the past years several articles have been published that report the use and the benefit of the ICF in the field of clinical work and SLTs' education (Ma *et al.* 2008, O'Halloran and Larkins 2008).

To facilitate the use of the ICF in PwMS' rehabilitation and to guide inter-professional assessments in PwMS, the Comprehensive ICF Core Set for MS has been developed at an international consensus conference according to an established multistage and decision-making process integrating evidence from preparatory studies (Coenen *et al.* 2011). SLTs were involved in
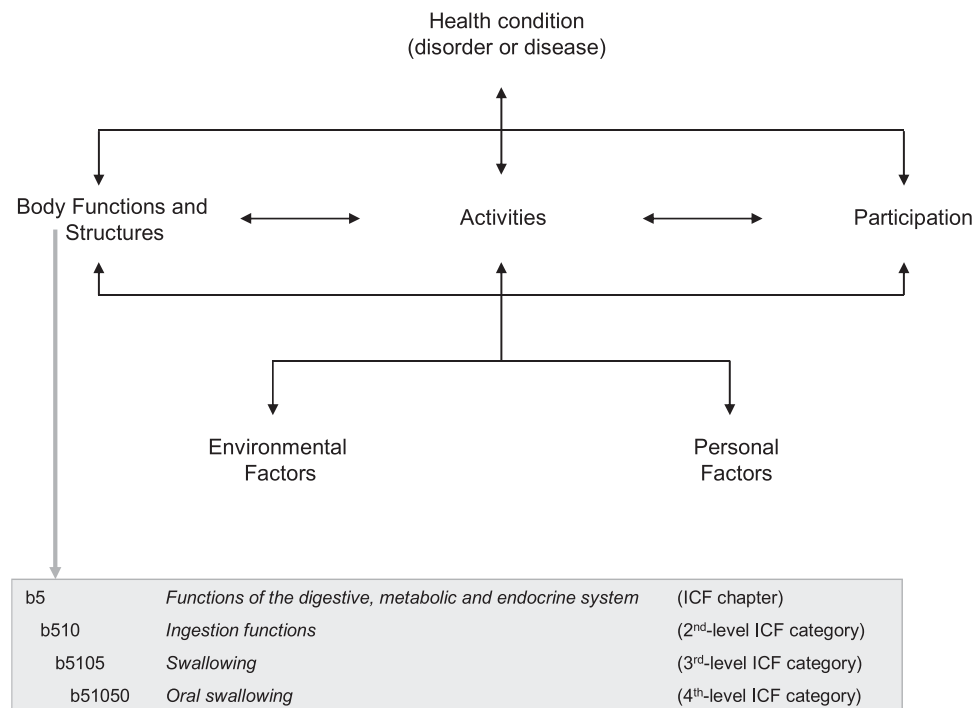
Figure 1. Biopsychosocial perspective of the ICF classification and its hierarchical structure.

one of the preparatory studies, namely an international internet-based expert survey and at the international consensus conference. Participants of this survey were 173 health professionals from 46 countries representing all WHO world regions who are experienced in the treatment, rehabilitation or care of PwMS (25 nurses, 20 occupational therapists, 28 physical therapists, 49 physicians, 25 psychologists, 11 social workers and 15 SLTs). Besides, one SLT (MR) attended the international consensus conference involving 21 experts representing different health professions.

The intended purpose of the Comprehensive ICF Core Set is for use in settings such as rehabilitation, in which a comprehensive multidisciplinary description and assessment of functioning is necessary (Bickenbach *et al.* 2012). The Comprehensive ICF Core Set is available as a pool of categories including as few categories as possible to be practical, but as many as necessary to describe the aspects of functioning relevant to PwMS in a comprehensive multidisciplinary assessment. Thus, the Comprehensive ICF Core Set for MS includes ICF categories of the four ICF components, namely 40 *Body-functions* categories (physiological functions of body systems including psychological functions), seven *Body-structures* categories (anatomical parts of the body such as organs and limbs), 53 *Activities-&-participation* categories (execution of a task or action by an individual and involvement in a life situation), and 38 *Environmental-factors* (physical, social and attitudinal environment in which people live and conduct their lives). It is im-

portant to note that the Comprehensive ICF Core Set for MS is not a health status measure in its own right. It is a comprehensive, agreed-upon list of aspects that are relevant for PwMS. The Comprehensive ICF Core Set for MS is intended as an international standard of what to measure and report (not how to measure it), and aim to facilitate the assessment, interpretation and aggregation of data for any kind of health information in any setting. Concerning the future use of the Core Set, it is envisioned that it serves as a reference pool of potentially relevant areas of functioning and disability to be drawn upon if necessary to describe functioning for a specific individual in a specific situation (Bickenbach *et al.* 2012). Especially in multidisciplinary clinical settings, the Comprehensive ICF Core Set for MS could be a comprehensive framework to structure the obtained information according to the biopsychosocial perspective of the ICF and to guide the treatment and rehabilitation process accordingly.

The Comprehensive ICF Core Set for MS is now undergoing validation from the user perspective for which it has been first developed. Since ICF Core Sets should serve as a standard for inter-professional assessment it is most important to ascertain whether the ICF categories included in the Comprehensive ICF Core Set for MS cover the specific intervention goals of health professionals involved in the inter-professional team to address problems in functioning important to PwMS. Moreover, the validation from the perspective of health professionals will contribute to the worldwide

acceptance and credibility of the Comprehensive ICF Core Set for MS.

The objective of this study is to validate the content of the Comprehensive ICF Core Set for MS from the perspective of SLTs involved in the treatment of PwMS. The specific aims are (1) to identify PwMS' problems and resources, as well as environmental aspects treated by SLTs, and (2) to explore to what extent these aspects are represented in the Comprehensive ICF Core Set for MS.

Methods

Study design

We performed a three-round, international e-mail survey based on the principles of the Delphi technique (Linstone and Turoff 1975). The Delphi technique is defined as a method to collect information about an issue or probable event to be used as a basis for planning and decision making involving a panel of 'informed individuals' (Hasson *et al.* 2000).

Participants

To recruit SLTs from all over the world we used several strategies: (1) SLT associations and organizations were contacted; (2) personal contacts of the authors were used to recruit experts known from former projects; (3) co-operation partners of the ICF Research Branch network were contacted; (4) SLTs were identified by internet and literature search; and (5) SLTs were identified by recommendations of already identified experts (snowball system; Biernacki and Waldford 1981). SLTs have to fulfil the following inclusion criteria to be involved in this study: (1) speech (language) pathologist or speech language therapist; (2) at least two years of experience in the treatment and rehabilitation of PwMS; (3) fluency in English language to contribute to the Delphi Study; and (4) accessibility to the internet and a personal e-mail account.

To ensure that the participants of the study were 'informed individuals' concerning MS rehabilitation, the initial information letter noted that participants should be 'SLTs experienced in the treatment of MS'. The first contact letter included an invitation to cooperate and detailed information of the aim, procedure and the time line of the study. SLTs who agreed to participate were included in the study. In total, 84 SLTs were identified and 46 of them agreed to participate.

Material and data collection

In Round 1 of the Delphi Study we sent an information letter and an Excel file to the participating SLTs. The Excel file included the following open-ended question 'What are MS patients' problems and resources as well as aspects of environment treated by speech and language therapists in patients with multiple sclerosis?'. The participants were requested to list these problems, resources and environmental factors as free text. In addition, the participants documented their expertise by a self-report on professional background, current professional activity, durations of professional and practical experiences with PwMS.

The participants had 3 weeks to return their responses. We sent reminders 1 week and 2 days before the deadline. Statements of the SLTs in Round 1 were linked to the most precise ICF categories according to standardized linking rules (Cieza *et al.* 2002, 2005). These linking rules are a well-established, sound procedure that enables information from different sources (e.g. qualitative data, items of outcome measures) to be translated ('linked') to the ICF classification. Hence, the SLTs' statements were assigned to ICF categories of the components *Body Functions*, *Body Structures*, *Activities & Participation* and *Environmental Factors*. Those statements that were not sufficient to make a decision about the most precise ICF category were assigned 'nd' (not definable). If a statement was a personal factor as defined in the ICF, the concept was assigned 'pf'. If a statement could not be linked to the ICF, it was assigned 'nc' (not covered).

Two health professionals (MR SLT; AC physical therapist) linked the participants' statements independently according to the linking rules mentioned above. Both health professionals were thoroughly trained on the ICF and the linking rules in a 1-week workshop performed by team members of the ICF Research Branch in Munich, Germany. In addition, both had practical experience in neurorehabilitation, especially in the treatment of PwMS. The linking results of the two health professionals were compared, and consensus was used to decide which ICF category should be linked to each statement. Disagreement was resolved in a structured discussion with a third expert (MC team member of the ICF Research Branch, psychologist) to create a final agreed-on list of linked ICF categories.

In Round 2, the participating SLTs received the group response linked to ICF categories and a summary of statements not linked to ICF categories (nc, pf). We asked them whether they agreed or not with the fact that the shown ICF categories represented problems and resources of PwMS, as well as environmental aspects, treated by SLTs. The answers were descriptively analysed (percentage of participants who agreed to the respective ICF categories).

In Round 3, the experts once more received the list of ICF categories and a summary of statements not linked to ICF categories containing the compiled group results
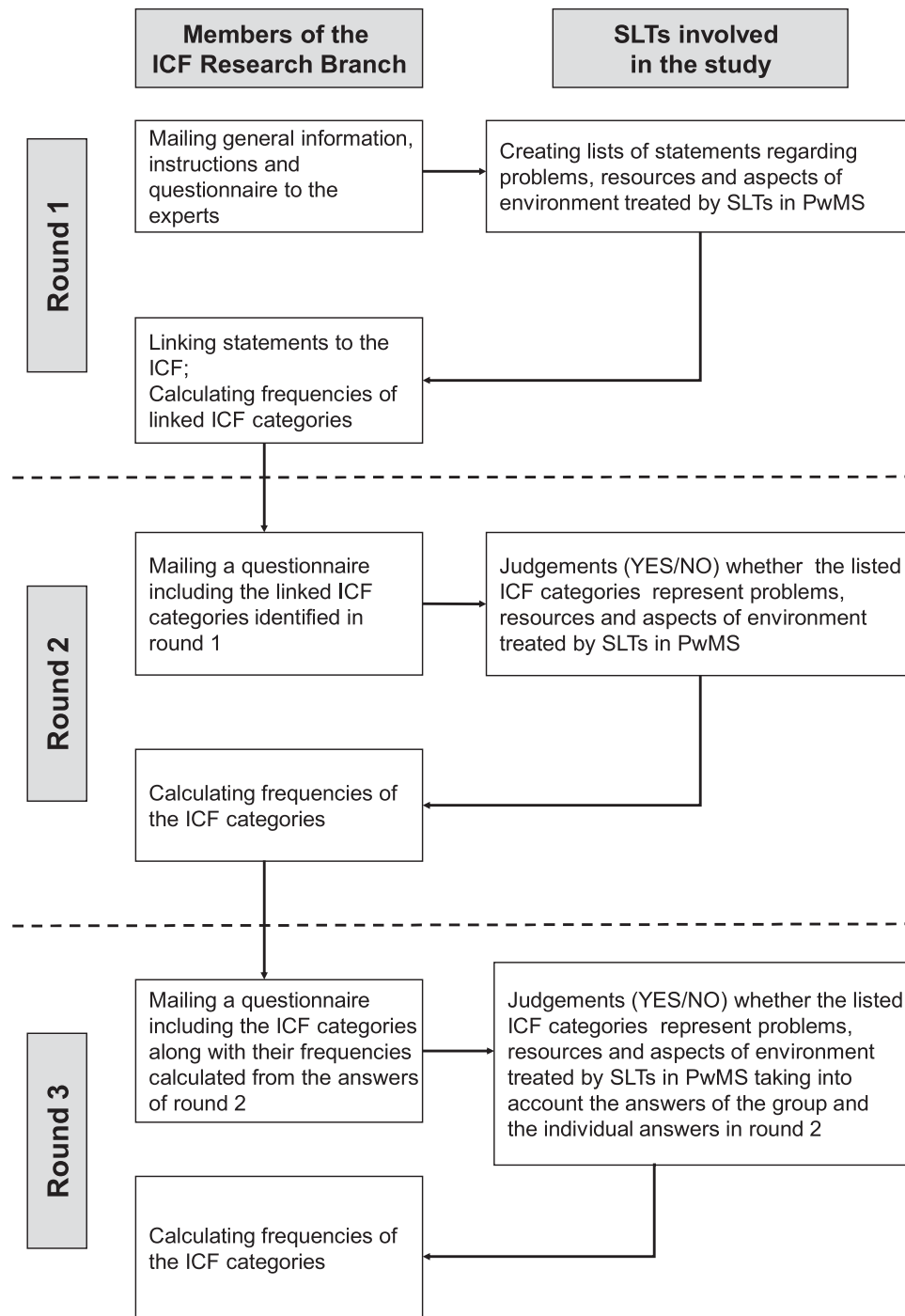
Round 1

Members of the ICF Research Branch	SLTs involved in the study

Mailing general information, instructions and questionnaire to the experts → Creating lists of statements regarding problems, resources and aspects of environment treated by SLTs in PwMS

Linking statements to the ICF;
Calculating frequencies of linked ICF categories

Round 2

Mailing a questionnaire including the linked ICF categories identified in round 1 → Judgements (YES/NO) whether the listed ICF categories represent problems, resources and aspects of environment treated by SLTs in PwMS

Calculating frequencies of the ICF categories

Round 3

Mailing a questionnaire including the ICF categories along with their frequencies calculated from the answers of round 2 → Judgements (YES/NO) whether the listed ICF categories represent problems, resources and aspects of environment treated by SLTs in PwMS taking into account the answers of the group and the individual answers in round 2

Calculating frequencies of the ICF categories

Figure 2. Description of the Delphi technique.

of Round 2 (percentage of 'Yes' answers) and their own answers. We then asked the participants whether these categories represent problems and resources of PwMS, as well as environmental aspects, treated by SLTs considering the group result in their final decision. The process of the Delphi Study with its three rounds is displayed in figure 2.

Data analysis

We used descriptive statistics to characterize the sample and frequencies of answers of Rounds 2 and 3. Kappa statistics with 95% bootstrapped confidence intervals (95%CI) (Cohen 1960, Vierkant n.d.) were calculated using SAS for windows v.9.1 (SAS Institute Inc., Cary, NC, USA) to analyse the agreement between the two

WHO region	Rounds			Female[a] n (%)	Age[a] Median (range)	Professional experience (years)[a] Median (range)	MS experience (years)[a] Median (range)	Self-rating expertise MS[a,b] Median (range)
	1 n	2 n	3 n					
European region[c]	24	21	19	22 (91.7)	43.0 (24–59)	16.0 (2–38)	10.0 (2–34)	4.0 (2–4)
Region of the Americas[d]	3	2	2	3 (100.0)	41.0 (35–50)	14.0 (11–27)	14.0 (6–14)	4.0 (4–5)
Western Pacific region[e]	7	7	7	6 (85.7)	28.0 (25–47)	7.0 (3–25)	4.0 (1–21)	3.0 (3–5)
Total	34	30	28	31 (91.2)	41.5 (24–59)	14.5 (2–38)	10.0 (1–34)	4.0 (2–5)

Notes: [a]Data of Round 1.
[b]1 = low, 5 = Excellent, self-report.
[c]Belgium (1), Denmark (1), Finland (1), France (2), Germany (3), Italy (1), Netherlands (2), Slovenia (1), Spain (5) and UK (7).
[d]Argentina (2) and United States (1).
[e]Australia (6) and China (1).

health professionals who performed the linking. The values of the kappa coefficient generally range from 0 to 1, whereas 1 indicates perfect agreement and 0 indicates no additional agreement beyond what is expected by chance alone. The degree of agreement was determined as described by Landis and Koch (1977).

We compared the linked ICF categories with the ICF categories included in the Comprehensive ICF Core Set for MS and identified two sets of ICF categories: confirmed and not-yet-included ICF categories. An ICF category was considered confirmed if the identical category at the same or higher level was included in the Comprehensive ICF Core Set for MS with an agreement of more than 75% of the participants (arbitrary cut-off). To give an example, the second-level category *b730 Muscle power function* was considered confirmed because at least one third-level category (*b7300 Power of isolated muscles and muscle groups*) included in it reached a level of agreement of more than 75%. An ICF category was considered not-yet-included if it was not included at the same or a higher level in the ICF Core Set and was agreed on by more than 75% of the participants.

Results

Participants

A total of 46 SLTs from 16 countries and familiar with the English language agreed to participate in the Delphi Study. Finally, 34 experts (73.9%) responded to Round 1 of the survey and sent back the filled-in questionnaire. Three participants called off their participation for temporal reasons. Nine participants did not respond in spite of three reminders. Table 1 shows the demographic and professional characteristics of the 34 experts involved in Round 1. The questionnaire of Round 2 was sent to all participants of Round 1 and was answered by 30 SLTs (30/46; 65.2%).

Twenty-eight of 30 SLTs (28/46; 60.9%) participated in Round 3.

Identified ICF categories

In Round 1, the participants provided 524 statements referring to problems and resources of PwMS, as well as aspects of environment, treated by SLTs. We linked these statements to 129 ICF categories, namely 60 *Body-functions* categories (28 second-level, 24 third-level and eight fourth-level categories), two *Body-structures* categories (one second-level and one third-level category), 42 *Activities-&-participation* categories (31 second-level and 11 third-level categories), as well as 25 *Environmental-factors* categories (17 second-level and eight third-level categories). The results and the participants' percentages of agreement of Round 3 are shown in tables 2–4.

The kappa statistic for the linking was 0.67 [95% CI = 0.64–0.70]. This result for the accuracy of the peer review is comparable with other studies reporting kappa statistics on the linking to ICF categories (Conrad *et al.* 2012b).

Comparison with the Comprehensive ICF Core Set for MS

The SLTs confirmed 28 categories in the Comprehensive ICF Core Set for MS: 12 *Body-functions* categories, nine *Activities-&-participation* categories and seven *Environmental-factors* categories. From these, seven second-level categories in the Comprehensive ICF Core Set for MS were additionally confirmed by 17 third-level categories (tables 2–4, grey shaded categories), namely, *b164 Higher-level cognitive functions, b310 Voice functions, b330 Fluency and rhythm of speech functions, d350 Conversation, d360 Using communication devices and techniques, e125 Products and technology for communication,* and *e580 Health services, systems and*

Table 2. Results of the Delphi Study: Identified categories of the ICF components *Body Functions* and *Body Structures*

ICF code			ICF title	Percentage of SLTs
2nd level	3rd level	4th level		
Confirmed categories (categories with an agreement ≥ 75%)				
	b1308		Energy and drive functions, other specified (fatigue)	75.0
b140			Attention functions	82.1
b144			Memory functions	78.6
b164			Higher-level cognitive functions	82.1
	b1641		Organization and planning[a]	75.0
b310			Voice functions	89.3
	b3100		Production of voice	89.3
	b3101		Quality of voice	89.3
b320			Articulation functions	89.3
b330			Fluency and rhythm of speech functions	89.3
	b3300		Fluency of speech	89.3
	b3301		Rhythm of speech	89.3
	b3302		Speed of speech	89.3
	b3303		Melody of speech	89.3
b445			Respiratory muscle functions	85.7
	b5104		Salivation	85.7
	b5105		Swallowing	89.3
	b51051		Pharyngeal swallowing	89.3
b730			Muscle power functions	71.4
	b7300		Power of isolated muscles and muscle groups	78.6
b760			Control of voluntary movement functions	82.1
Not-yet-included categories (with an agreement ≥ 75%)				
b122			Global psychosocial functions	89.3
b167			Mental functions of language	89.3
	b1670		Reception of language	85.7
		b16700	Reception of spoken language	85.7
		b16701	Reception of written language	85.7
	b1671		Expression of language	89.3
		b16710	Expression of spoken language	89.3
		b16711	Expression of written language	89.3
b440			Respiration functions	85.7
	b4402		Depth of respiration	85.7
b450			Additional respiratory functions	85.7
b510			Ingestion functions	89.3
	b5102		Chewing	89.3
	b5103		Manipulation of food in the mouth	89.3
Not-confirmed categories (with an agreement < 75%)				
b114			Orientation functions	–
b126			Temperament and personality functions	–
	b1300		Energy level	–
	b1301		Motivation	71.4
b134			Sleep functions	–
b152			Emotional functions	42.9
b156			Perceptual functions	–
b210			Seeing functions	28.6
b235			Vestibular functions	–
b260			Proprioceptive function	39.3
b265			Touch function	21.4
b270			Sensory functions related to temperature and other stimuli	46.4
b280			Sensation of pain	–
b455			Exercise tolerance functions	–
b525			Defecation functions	–
	b5500		Body temperature	–
	b5508		Thermoregulatory functions, other specified (Sensitivity to heat)	–
	b5508		Thermoregulatory functions, other specified (Sensitivity to cold)	–

[a]

Continued

Table 2. Continued

ICF code			ICF title	Percentage of SLTs
2nd level	3rd level	4th level		
b620			Urination functions	–
b640			Sexual functions	–
b710			Mobility of joints	–
b735			Muscle tone functions	60.7
b740			Muscle endurance functions	–
b750			Motor reflex functions	–
	b7650		Involuntary contractions of muscles	–
	b7651		Tremor	–
b770			Gait pattern functions	–
b780			Sensations related to muscles and movement functions	–
s110			Structure of brain	–
s120			Spinal cord and related structures	–
s610			Structure of urinary system	–
s730			Structure of upper extremity	–
s750			Structure of lower extremity	–
s760			Structure of trunk	–
s810			Structure of areas of skin	59.2

Note: [a]ICF categories that have been reported by the SLTs with an agreement of ≥ 75% and which are not included in the Comprehensive ICF Core Set for MS at this level of specification (e.g. 'b1641 Organization and planning' is not included in the Comprehensive ICF Core Set for MS; however, its lower-level category 'b164 Higher-level cognitive functions' is included and confirmed by the SLTs).
The table shows ICF categories reported by the participants of the Delphi Study (categories with percentage), namely (1) confirmed categories: ICF categories included in the Comprehensive ICF Core Set for MS that were confirmed by the SLTs with an agreement of ≥ 75%, (2) not-yet-included categories: ICF categories that have been reported by the SLTs with an agreement of ≥ 75% and that are not included in the Comprehensive ICF Core Set for MS, and (3) not-confirmed categories: ICF categories included in the Comprehensive ICF Core Set for MS that were not confirmed by the SLTs (agreement of < 75%).

policies. Additionally, the third-level ICF category *b5105 Swallowing* was confirmed by the fourth-level category *b51051 Pharyngeal swallowing.*

Twelve second-level ICF categories were identified as not-yet-included ICF categories: five *Body-functions* categories, five *Activities-&-participation* categories and two *Environmental-factors* categories (tables 2–5). In addition, four *Personal Factors* referring to the abilities of PwMS in managing their MS-related problems and resources in a positive or negative way were identified: 'Coping with communication issues at work and home' (92.9%), 'insight of communication difficulties' (92.9%), 'lack of self-confidence when speaking' (92.9%), and 'self-image' (75.0%). Finally, the participating SLTs agreed with the not-covered issue 'counselling and support for families/carers' (92.9%), as well as the health condition 'chest infections (Risk of aspiration related chest infections)' (92.9%), as important problems of PwMS to be taken into account in the treatment of SLTs.

Discussion

In this study, problems and resources of PwMS, as well as environmental aspects relevant to SLTs, were identified using the Delphi technique. Especially *Body-functions* and *Activities-&-participation* categories of the Comprehensive ICF Core Set for MS were confirmed from the perspective of SLTs. In addition, we identified a few categories not included in the current version of the Comprehensive ICF Core Set for MS. The results of

this study support the content validity of the Comprehensive ICF Core Set for MS from the perspective of SLTs and emphasize functioning in PwMS from a comprehensive point of view and the influence of environmental factors.

Within the ICF component *Body Functions* the SLTs confirmed 12 categories of the ICF Core Set at the same or a higher level of classification. These categories from chapters *b1 Mental functions, b3 Voice and speech functions, b4 Functions of the cardiovascular, haematological, immunological and respiratory systems, b5 Functions of the digestive, metabolic and endocrine system,* and *b7 Neuromusculoskeletal and movement-related functions* highlight the broad range of body functions treated by SLTs. Some of these categories are discussed in detail.

If motor and sensory deficits impact on the orofacial, pharyngeal, laryngeal or respiratory muscles, PwMS may experience dysarthria (speech and voice impairment) and dysphagia (swallowing disturbances). Dysarthria is the most well-known communication disturbance in PwMS and usually includes spastic and ataxic features (Hartelius *et al.* 2000). The SLTs of our study confirmed three categories of chapter 3 (*b310 Voice functions, b320 Articulation functions, b330 Fluency and rhythm of speech functions*) and one category of chapter 4 (*b445 Respiratory muscle functions*) which are directly related to dysarthria. Dysphagia in PwMS covered by the ICF category *b5105 Swallowing* is strongly associated with brainstem and cerebellar damage (Calcagno *et al.* 2002, Thomas and Wiles 1999). Two categories of chapter 5

Table 3. Results of the Delphi Study: Identified categories of the ICF component *Activities & Participation*

ICF code			
2nd level	3rd level	ICF title	Percentage of SLTs
Confirmed categories (categories with an agreement ≥ 75%)			
d163		Thinking	82.1
d166		Reading	85.7
d170		Writing	85.7
d175		Solving problems	78.6
d330		Speaking	82.1
d350		Conversation	89.3
	d3500	Starting a conversation[a]	89.3
	d3501	Sustaining a conversation	89.3
	d3504	Conversing with many people	89.3
d360		Using communication devices and techniques	89.3
	d3600	Using telecommunication devices	82.1
	d3601	Using writing machines	89.3
d550		Eating	85.7
d560		Drinking	85.7
Not-yet-included categories (with an agreement ≥ 75%)			
d310		Communicating with—receiving—spoken messages	89.3
d325		Communicating with—receiving—written messages	82.1
d335		Producing nonverbal messages	85.7
	d3350	Producing body language	85.7
d345		Writing messages	85.7
d355		Discussion	89.3
Not-confirmed categories (with an agreement < 75%)			
d110		Watching	–
d155		Acquiring skills	–
d160		Focusing attention	–
d177		Making decisions	–
d210		Undertaking a single task	–
d220		Undertaking multiple tasks	–
d230		Carrying out daily routine	42.9
d240		Handling stress and other psychological demands	–
d410		Changing basic body position	–
d415		Maintaining a body position	25.0
d420		Transferring oneself	–
d430		Lifting and carrying objects	–
d440		Fine hand use	17.9
d445		Hand and arm use	10.7
d450		Walking	–
d455		Moving around	–
d460		Moving around in different locations	–
d465		Moving around using equipment	–
d470		Using transportation	–
d475		Driving	–
d510		Washing oneself	–
d520		Caring for body parts	–
d530		Toileting	–
d540		Dressing	–
d570		Looking after one's health	–
d620		Acquisition of goods and services	–
d630		Preparing meals	32.1
d640		Doing housework	10.7
d650		Caring for household objects	–
d660		Assisting others	–
d710		Basic interpersonal interactions	–
d720		Complex interpersonal interactions	–
d750		Informal social relationships	53.6
d760		Family relationships	50.0
d770		Intimate relationships	28.6

Continued

Table 3. Continued

ICF code		ICF title	Percentage of SLTs
2nd level	3rd level		
d825		Vocational training	–
d830		Higher education	–
d845		Acquiring, keeping and terminating a job	–
d850		Remunerative employment	39.3
d860		Basic economic transaction	–
d870		Economic self-sufficiency	28.6
d910		Community life	42.9
d920		Recreation and leisure	60.7
d930		Religion and spirituality	–

Note: [a]ICF categories that have been reported by the SLTs with an agreement of ≥ 75% and that are not included in the Comprehensive ICF Core Set for MS at this level of specification (e.g. 'd3500 Starting a conversation' is not included in the Comprehensive ICF Core Set for MS; however, its lower-level category 'd350 Conversation' is included and confirmed by the SLTs).

The table shows ICF categories reported by the participants of the Delphi Study (categories with percentage), namely (1) confirmed categories: ICF categories included in the Comprehensive ICF Core Set for MS that were confirmed by the SLTs with an agreement of ≥ 75%, (2) not-yet-included categories: ICF categories that have been reported by the SLTs with an agreement of ≥ 75% and that are not included in the Comprehensive ICF Core Set for MS, and (3) not-confirmed categories: ICF categories included in the Comprehensive ICF Core Set for MS that were not confirmed by the SLTs (agreement of < 75%).

that have been confirmed by the SLTs are related to dysphagia, namely *b5104 Salivation* and *b5105 Swallowing*.

There are other body functions confirmed by the participating SLTs that also play an important role in communication, i.e. cognitive and behavioural impairments. It is known that about 63% of PwMS may experience high-level-language impairments (Klugman and Ross 2002) including word-finding problems and difficulties in managing expressive and comprehensive subtleties of language, both oral and written (Arnott *et al.* 1997, Lethlean and Murdoch 1997). These impairments are closely related to cognitive changes such as slowed information processing, disturbances in attention, memory, and executive functions (Chiaravalloti and DeLuca 2008). Correspondingly, the SLTs confirmed four categories included in the Comprehensive ICF Core Set for MS, namely *b1308 Energy and drive functions, other specified (fatigue), b140 Attention functions, b144 Memory functions*, and *b164 Higher-level cognitive functions*.

From the component *Activities & Participation,* study participants confirmed ICF Core Set categories related to both oral and written communication represented by the categories *d166 Reading, d170 Writing, d330 Speaking*, and *d350 Conversation*. Besides, categories referring to thinking and solving problems (*d164 Thinking, d175 Solving problems*) have been confirmed by the SLTs addressing the impact of cognitive and neurolinguistic impairments on communication. The confirmed category *d360 Using communication devices and techniques* covers the need of some PwMS to use alternative and augmentative communication devices.

Several *Environmental-factors* categories included in the Comprehensive ICF Core Set for MS have been confirmed by the participating SLTs. The category *e1108 Special formulations of food to maintain safety and nu-*

trition has been confirmed addressing the importance of diet modification in moderate dysphagia in MS. The category *e125 Products and technology for communication* reminds again of the possible usefulness of alternative and augmentative communication devices for PwMS with severe speech and voice impairments. The confirmed ICF Core Set categories *e310 Immediate family*, *e320 Friends*, *e340 Personal care providers and personal assistants*, and *e355 Health professionals* stress the outstanding importance of the social environment and support for PwMS. A realistic and constructive awareness of problems and strategies and the (communicative) interaction of PwMS and their social network are some of the very crucial factors that should never be forgotten.

In addition to the confirmed ICF categories discussed above, the participating SLTs agreed on 12 second-level categories that are not yet included in the Comprehensive ICF Core Set for MS. In the *Body Functions* component five categories were identified as not-yet-included categories. The first one, *b122 Global psychosocial functions* is associated with the pragmatic dimension of communication, which allows subjects to be effective and adequate when communicating in different situations. Voice tone, gestures, type or words selected for different occasions are some examples in this context (Baylor *et al.* 2011). The second category, *b167 Mental functions of language,* is related to the specific language impairments that can be affected in MS. Although aphasia is rare in MS and although many of the cognitive-related communication problems are associated to a more general cognitive impairment, this category is clearly related to specific linguistic impairments in PwMS that can also be found (Prakash *et al.* 2008). Finally, the categories *b440 Respiration functions* and *b450 Additional respiratory functions* were considered as

Table 4. Results of the Delphi Study: Identified categories of the ICF component *Environmental Factors*

ICF code		ICF title	Percentage of SLTs%
2nd level	3rd level		
Confirmed categories (categories with an agreement ≥ 75%)			
	e1108	Products or substances for personal consumption, other specified (Special formulations of food to maintain safety and nutrition)	92.9
e125		Products and technology for communication	89.3
	e1250	General products and technology for communication ᵃ	89.3
	e1251	Assistive products and technology for communication	92.9
e310		Immediate family	78.6
e320		Friends	75.0
e340		Personal care providers and personal assistants	92.9
e355		Health professionals	92.9
e580		Health services, systems and policies	85.7
	e5800	Health services	89.3
Not-yet-included categories (with an agreement ≥ 75%)			
	e1100	Food	75.0
e535		Communication services, systems and policies	78.6
Not-confirmed categories (with an agreement < 75%)			
	e1101	Drugs	–
e115		Products and technology for personal use in daily living	71.4
e120		Products and technology for personal indoor and outdoor mobility and transportation	–
e135		Products and technology for employment	–
e150		Design, construction and building products and technology of buildings for public use	–
e155		Design, construction and building products and technology of buildings for private use	–
e165		Assets	–
	e2250	Temperature	–
	e2251	Humidity	–
	e2253	Precipitation	–
e315		Extended family	53.6
e325		Acquaintances, peers, colleagues, neighbours and community members	–
e330		People in positions of authority	64.3
e360		Other professionals	–
e410		Individual attitudes of immediate family members	–
e415		Individual attitudes of extended family members	–
e420		Individual attitudes of friends	–
e425		Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	–
e430		Individual attitudes of people in positions of authority	–
e440		Individual attitudes of personal care providers and personal assistants	–
e450		Individual attitudes of health professionals	–
e460		Societal attitudes	53.6
e515		Architecture and construction services, systems and policies	–
e525		Housing services, systems and policies	–
e540		Transportation services, systems and policies	–
e550		Legal services, systems and policies	
e555		Economic services, systems and policies	64.3
e570		Social security services, systems and policies	
e575		General social support services, systems and policies	
e585		Education and training services, systems and policies	42.9
e590		Labour and employment services, systems and policies	42.9

Notes: ᵃICF categories that have been reported by the SLTs with an agreement of ≥ 75% and that are not included in the Comprehensive ICF Core Set for MS at this level of specification (e.g. 'e1250 General products and technology for communication') are not included in the Comprehensive ICF Core Set for MS; however, its lower-level category 'e125 Products and technology for communication' is included and confirmed by the SLTs).

The table shows ICF categories reported by the participants of the Delphi Study (categories with percentage), namely (1) confirmed categories: ICF categories included in the Comprehensive ICF Core Set for MS that were confirmed by the SLTs with an agreement of ≥ 75%, (2) not-yet-included categories: ICF categories that have been reported by the SLTs with an agreement of ≥ 75% and that are not included in the Comprehensive ICF Core Set for MS, and (3) not-confirmed categories: ICF categories included in the Comprehensive ICF Core Set for MS that were not confirmed by the SLTs (agreement of < 75%).

Table 5. Summary of the results of the Delphi Study

	Body Functions *n*	Body Structures *n*	Activities & Participation *n*	Environmental Factors *n*	Total *n*
ICF categories in the Comprehensive ICF Core Set for MS	40	7	53	38	138
Confirmed ICF categories with agreement ≥ 75%	12	0	9	7	28
Not confirmed ICF categories with agreement < 75%	28	7	44	31	110
Not-yet-included ICF categories in the Comprehensive ICF Core Set for MS with agreement ≥ 75% (at the second level of classification)	5	0	5	2	12

not-yet-included categories which should be taken into account when treating PwMS. Both categories were also identified in the Delphi Study to validate the Comprehensive ICF Core Set for MS from the perspective of physical therapists (Conrad *et al.* 2012b).

From the *Activities & Participation* component the SLTs agreed on several not-yet-included categories of chapter *d3 Communication*. The categories *d310 Communicating with receiving spoken messages, d325 Communicating with receiving written messages, d335 Producing nonverbal messages, d345 Writing messages*, and *d355 Discussion* seem to overlap with the more general categories *d166 Reading, d170 Writing*, and *d330 Speaking*. Whereas the later ones are clearly related to linguistic functions, the d3 categories are more complex in nature. From a SLT point of view it is important to take them into account in addition to the Comprehensive ICF Core Set for MS to describe communication-related issues of PwMS as comprehensive and detailed as possible. The need of using especially the category *d345 Writing messages* in addition to the Comprehensive ICF Core Set for MS is also supported by the Delphi Study including occupational therapists (Conrad *et al.* 2012a).

In the *Environmental Factors* component *e1100 Food* and *e535 Communication services, systems and policies* were identified as not-yet-included categories. Food is a product that has to be considered when approaching dysphagia. The second one is relevant because it directly addresses the availability and accessibility of communication channels for PwMS (e.g. alternative and augmentative communication devices).

Beside the ICF categories discussed above, the SLTs involved in this study agreed on a small number of personal factors. The impact of personal factors, such as 'coping with communication issues at work and home', 'loss of control', 'insight of communication difficulties' (in the sense of self-perception), 'lack of self-confidence when speaking', and 'self-image', on PwMS' well-being and quality of life is obvious. It is well-known that SLTs treating PwMS are often confronted with these factors. In addition to these personal factors, one issue not covered by the ICF, namely 'counselling and support for families/carers', was agreed upon by the participating SLTs.

This finding strengthens the importance of comprehensively informing family members or carers of PwMS about the disease, as well as linguistic and speech-related problems.

As the Comprehensive ICF Core Set for MS is a tool to describe functioning in PwMS it can be used in clinical assessment, assignment to interventions and health services, as well as in planning and performing interventions and evaluation of outcomes (Steiner *et al.* 2002). Thus, the ICF Core Set for MS 'helps to standardize and structure the description of functioning and, as a result, to guide the assessment' (Bickenbach *et al.* 2012: 22). Especially in inter-professional clinical settings the Comprehensive ICF Core Set for MS is a framework to structure the clinical information according to the biopsychosocial perspective of the ICF and to guide the treatment and rehabilitation process accordingly. It can be integrated in SLTs' clinical work with PwMS to facilitate goal setting and the assignment of intervention targets to specific interventions, to document intervention goals in a standardized way, and to evaluate goal achievement. Besides, it can be used to create a categorical profile across ICF categories as illustrated in figure 3. This profile provides a useful guide for the planning, follow-up, and reporting of healthcare interventions (Rauch *et al.* 2008). A case example how to use the Comprehensive ICF Core Set for MS in clinical practice is illustrated elsewhere (Glässel and Lückenkemper 2012).

It is important to mention that the Comprehensive ICF Core Set for MS offers a list of the most relevant ICF categories to assess PwMS' functioning in neurorehabilitation. Its application does not prevent the users from adding additional ICF categories if these are thought necessary for the user's purposes. Therefore, it might be worthwhile for SLTs to use also the not-yet-included categories identified in this study when assessing functioning and environmental factors of PwMS in clinical practice. Beside its use in inter-professional rehabilitation the Comprehensive ICF Core Set for MS can be used or can be of benefit for example in the documentation and storage of electronic medical records, the analyses of effectiveness of interventions, the

Figure 3. Categorical profile across ICF categories.
ICF qualifier: 0=no impairment/restriction; 1=mild impairment/restriction; 2=moderate impairment/restriction; 3=severe impairment/restriction; 4=complete impairment/restriction.

development of ICF-based or ICF-compatible assessments and in introducing the ICF as a common language for all healthcare practitioners, patients and their families.

Limitations

There are some limitations that should be mentioned. Participants from three WHO world regions took part in this Delphi Study guaranteeing a wide range of expert opinion. However, it was not possible to recruit SLTs from the Southeast Asia, the Eastern Mediterranean, and the African Regions. This can be explained by limited accessibility to internet, problems with the English language or not-yet-developed networking of SLTs experienced in the treatment of PwMS in these regions. In addition, this limitation can be determined by the low prevalence rates of MS in Southeast Asia and the African Regions (WHO 2008) and consequently by the non-availability of MS-specific healthcare services and specialists health professionals in these world regions. Unfortunately, we could not prevent a reduction of the participants' number in the three Delphi rounds. One of the main reasons seems to be the considerable workload and the duration of the data collection. Nevertheless, the overall response rate is comparable with other validation studies (Berno *et al.* 2012, Conrad *et al.* 2012a, 2012b). Furthermore, two health professionals (MR, AC) performed the linking process according to established linking rules. However, it remains unclear whether other health professionals would have

decided differently. Besides, the two health professionals have different professional backgrounds (SLT, physical therapist) which could have influenced the linking process. A further limitation concerns the 75% cut-off for the participants' consensus. Although this cut-off was applied at the consensus conference to select the categories to be included in the Comprehensive ICF Core Set for MS and in previous ICF Core Sets validation studies (Berno *et al.* 2012, Conrad *et al.* 2012a, 2012b), it still remains, to some extent, arbitrary. We are aware that a higher cut-off (e.g. 90%) would generate very few agreed upon categories whereas a lower cut-off (e.g. 60%) would generate more categories. Finally, it is important to emphasize that this study focuses on the content validity of the Comprehensive ICF Core Set for MS, and represents only one of many perspectives based on which the validity is being studied. Therefore, other Delphi studies including physicians (Berno *et al.* 2012), (neuro-)psychologists, nurses, physical therapists (Conrad *et al.* 2012b), and occupational therapists (Conrad *et al.* 2012a) have been started in parallel. Moreover, the validity of the ICF Core Set is further being explored using statistical methods.

Conclusions

The Comprehensive ICF Core Set for MS serves as a pool of categories to describe functioning in settings in which a comprehensive description and assessment of functioning is necessary. This study contributes to the content validity of the ICF categories included in this

Comprehensive ICF Core Set and outlines which areas of functioning and health are relevant for PwMS and should consequently be assessed from the perspective of SLTs. It can be the starting point for further studies focusing on the identification of adequate outcome measures to assess the ICF categories included in the Comprehensive ICF Core Set for MS. Besides, it is important to develop strategies for the implementation of the Comprehensive ICF Core Set for MS in clinical practice. The findings of this study, as well as the results of completed and ongoing validation studies, will further elucidate the validity of the Comprehensive ICF Core Set for MS.

The results of the study also pinpoint to the need of SLTs' involvement in the development and validation of further ICF Core Sets to strengthen their areas of expertise and to select categories that are relevant for rehabilitation of speech- and language-related problems. Besides, SLTs are invited to contribute to the ICD-ICF joint use initiative which has already been initiated by WHO aiming to supplement the ICD-11 with functioning properties (ICF categories) that are relevant for specific health conditions. The decision on properties to be included will be based beside others on ICF Core Sets such as the ICF Core Set for MS.

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