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The activities and participation categories of the ICF Core Sets for multiple sclerosis from the patient perspective

Authors:
Karhula ME [1, 2]
Kanelisto KJ [1]
Ruutiainen J [3]
Hämäläinen PI [4]
Salminen A-L[5]

[1]GeroCenter Foundation for Research and Development, Kinkomaa, Finland
[2] Department of Health Sciences, Jyväskylä University, Jyväskylä, Finland
[3]Finnish MS Society, Masku, Finland
[4]Masku Neurological Rehabilitation Centre, Masku, Finland
[5]The Social Insurance Institution of Finland, Helsinki, Finland

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Corresponding author: Maarit E Karhula, M.Sc. Email: maarit.karhula@gmail.com,
[1]GeroCenter Foundation for Research and Development, Vitapolis, Parantolantie 24, FI-40930 Kinkomaa, Finland
+358405276016

Abstract

Purpose: To validate the activities and participation components of The International Classification of Functioning, Disability and Health (ICF).

Methods: In this cross-sectional study, 113 Finnish community-dwelling persons with MS were assessed using a semi-structured interview provided by the Canadian Occupational Performance Measure (COPM) to capture participants' self-perceived problems in everyday activities and participation. Problems were linked to the ICF categories.

Results: Participants identified 527 of the most important occupational performance problems. They covered all chapters of the ICF Activities and Participation components. Forty-one categories out of a total 53 ICF activities and participation categories of the Comprehensive ICF Core Set and four out of five categories of the Brief ICF Core Set were reported on by the participants. The most common category in this sample, 'd920 Recreation and leisure' (145 problems/ 27.5%), is not included in the Brief ICF Core Set.

Conclusions: Most, but not all, ICF activities and participation categories of the ICF Core Sets for MS could be confirmed from the perspective of persons with MS. It is worth considering to add category 'd920 Recreation and leisure' to the Brief ICF Core Set.

Implication for Rehabilitation

- The perceived problems of persons with MS support current versions of the ICF Core Sets for MS.
- The subjective experiences of prioritized problems encountered in everyday life vary considerably among community-dwelling persons with MS.
- Persons with MS often experience problems with recreation and leisure activities.
- Experiences of patient about recreation and leisure activities should be asked more systematically during rehabilitation process and the role of recreation and leisure should be considered when further developing the Brief ICF Core Sets for MS.

Introduction

Multiple Sclerosis (MS) is the most common chronic disabling disease of the central nervous system in young adults. From a lifelong perspective, the course of the disease is unpredictable, most often progressive and polysymptomatic [1]. Common manifestations include fatigue, bladder and bowel disorders, problems with vision, tremors, spasticity, abnormal speech, swallowing disorders, sexual dysfunction, cognitive impairment, mobility problems, pain and depression. All of these, in different combinations, seriously affect the daily activities of persons with MS and their possibilities to actively participate in community [2] .

The International Classification of Functioning, Disability and Health (ICF) [3] connects body, individual and societal perspectives. The ICF contains the following broad components: body functions and structures, activities and participation and environmental factors, as well as personal factors which are not yet coded in the ICF (figure 1). The Activity and Participation component includes nine chapters which consist of 21 domains, 118 second-level categories and approximately 400 third- and fourth-level categories. Altogether, the ICF classification consists of more than 1400 categories.

Insert figure 1 about here

The ICF Core Sets for specific diseases have been developed to serve as tools for applying the ICF in clinical practice [4]. ICF Core Sets are lists of ICF categories selected to capture those aspects of functioning that are most likely affected by a specific disease. ICF Core Sets have been developed through a formal decision-making and consensus process using knowledge from recent studies. The perspective of person with specific disease has been identified via interviews and the expert perspective has been collected via a survey [5].

The Comprehensive and Brief Core Sets for MS were decided upon at the International Consensus Conference [6]. A systematic review identified 269 studies published between 2002 and 2007 concerning areas of functioning, disability and health [6]. Hundred and seventy-three health professionals from 46 countries represented the expert perspective in the Internet-based expert survey [6] and 27 persons with MS represented the perspective of persons with MS on focus groups [7]. Moreover, application of the ICF categories for 205 persons with MS was evaluated via a

multicentre empirical study in Germany and Switzerland [8]. The consensus conference included 138 ICF categories in the Comprehensive ICF Core Set for MS. Fifty-three of the categories represented the Activities and Participation component. The Brief Core Set for MS, which includes 18 categories, represents the minimum standard for the description and assessment of functioning in different settings. Five categories of them represent the Activities and Participation component: 'd175 Solving problems', 'd230 Carrying out daily routines', 'd450 Walking', 'd760 Family relationship' and 'd850 Remunerative employment'. Both ICF Core Sets for MS warrant further validation and worldwide applicability studies [6].

During the developmental process of the ICF Core Sets for MS, only one study took into account the perspective of persons with MS [7]. Therefore, it is important to further investigate the validity of the ICF Core Sets from the point of view of the persons with MS using the methods that highlight the priorities of the persons themselves.

The objective of our study was to add evidence to the validation of the activities and participation categories of the ICF Core Sets for MS from the perspective of persons with MS. The specific aim was to explore the problems in everyday activities and participation as perceived by persons with MS.

Material and methods

Design

The study was a multi-centre, cross-sectional study involving participants from the districts of Helsinki, Kuopio, Turku, Jyväskylä and Lahti. The procedure was approved by a Research Ethics Committee of the Finnish Social Insurance Institution. All of the participants gave their written informed consent according to the Declarations of Helsinki 1996 for participation in the study.

Participants

The sample included all participants attending to a two-year multi-professional, group-based out-patient rehabilitation project for persons with MS arranged by the Finnish MS Society together with Finnish Social Insurance Institution, and a comparison group of persons with MS receiving typical care. The inclusion criteria were as follows: (1) aged between 18 and 62 (inclusive) years, (2) a confirmed diagnosis of MS [9] (3), restrictions on functioning in at least two out of the four following domains: cognition, mood, fatigue and body control. Due to the intentions of the multicentre study (see "design"above) mildly disabled and those who were expected not to benefit from group therapy sessions were excluded if one or more of

the following criteria were met: (1) a Mini Mental State Examination (MMSE) score of below 20/30 (severe cognitive decline) [10], (2) a Beck Depression Inventory II score of over 40/63 (severe depression) (BDI-II) [11], (3) an Expanded Disability Status Scale (EDSS) of under 4.0 or over 8.5 [12] and (5) any other medical or mental condition precluding participation.

Methods

The data for the study was collected between July and November of 2010 at the beginning of a two-year, multi-professional, group-based out-patient rehabilitation project for persons with MS. Socio-demographic data, including gender, age and housing and working status, and characteristics about the disease, including the duration of the disease and the disease subtype, were collected. The disability of the participants was evaluated using the EDSS and Barthel Index [13]. The EDSS score ranges in increments of 0.5 from 0 (no impairment) to 10 (death). The lower EDSS grades (0-3.5) are defined by the signs in a neurological examination, while grades 4 and above are largely dependent on ambulation and the use of the upper extremities [12].The Barthel Index is a 21-point scale, where zero represents the greatest dependency and 20 independency with the help of others. Each item describes the discrete activity of a daily living task function, such as bowels, bladder, grooming, toilet use, feeding, transfer, mobility, dressing, walking up and down stairs, and bathing [13]. Depression was measured using the BDI-II. It is a 21-item self-assessment inventory of the symptoms of depression in which a higher score represents more problems with mood. A total score of between 14 and 19 is considered to be a sign of mild depression, between 20 and 28 to be a sign of moderate depression, and between 29 and 63 to be a sign of severe depression [11].

The Canadian Occupational Performance Measure (COPM) was used to capture participants' self-perceived problems in everyday activities and participation. Four occupational therapists who were trained to use the COPM in a similar way interviewed the participants during home visits. The COPM is a semi-structured interview designed to identify activities that the participant wants, needs or is expected to perform [14]. In the first phase of the interview, the participant reported those activities that he/ she found difficult to perform. Then each participant rated the importance of each activity using a 10-point scale, with one being not important at all and ten being extremely important. Then, the participant identified up to five activities that she/he considered to be the most important. Finally, the participant rated his/her performance of and satisfaction with these activities. However, this phase of the assessment is not reported in the present report.

Data analysis and linking the data to the ICF activities and participation categories

Problems that the participants prioritized as being most important (1-5 problems per participant) were linked to the corresponding ICF categories based on established rules [15,16] to confirm a systematic and standardized linking process. Before starting the linking process, the researchers (MK & KK) discussed and confirmed the linking and consensus rules. A perceived problem was handled as a unit of analysis which was coded to one ICF category according to the meaning of the perceived problem. For example, if the activity 'moving around and enjoying nature' was experienced by participant as a leisure activity in terms of spending time in nature, it was linked to ICF chapter 'd9 Community, social and civic life', and not to ICF chapter 'd4 Mobility'. Likewise, during the linking process researchers considered the occasions or context within which the problematic activity occurs and took that into account when linking the activity to ICF category. If needed, the researchers confirmed the meaning of the activity experienced by the participant with the researcher who interviewed the participant. During linking process, researchers documented activities which needed to be considered more closely and the reason for the additional judgment. First, one researcher (MK) linked problems to the ICF second-level categories. Then, another researcher (KK) agreed or disagreed with the choices. After that, the researchers discussed the points of disagreement and reached a consensus. A third researcher (A-LS) was available for consultation in situations in which a consensus could not be reached.

Results:

The characteristics of the participants (n=113) are reported in Table 1. All of the participants had moderate to severe disability and most were economically inactive. The mean of the EDSS score was 6.0 and ranged from 4.0 to 8.5. Majority of the participants were on disability pension (80 %).

Insert table 1. about here.

Linking perceived problems to the ICF activities and participation categories

In the COPM interview, the participants identified 527 of the most important problems that imposed activity limitations and participation restrictions (Table 2). The number of the most important problems identified per participant varied from one to five. We linked the perceived problems in all of the ICF activity and participation chapters and frequently to the following chapters to following degree: 'd4 Mobility' (25.4%), 'd5 Self-care' (15.9%), 'd6 Domestic life' (18.6%) and 'd9 Community, social and civic life' (27.7%). Infrequently, problems were linked to the chapters 'd1 Learning and applying knowledge' (1.7%), 'd3 Communication' (0.6%) and ' d7 Interpersonal interaction and relationships' (2.3%).Further, we linked the perceived problems to 43 second level ICF categories. In total 145 problems (27.5%) were linked to the second-

level category 'd920 Recreation and leisure'. The activities in this category varied considerably; they included, for example, enjoying nature, meeting friends, doing crosswords, doing sports/exercising, swimming, going to a concert, movie or theatre and doing handicrafts.
Most of the activities could clearly be linked to ICF categories; for example, the activity 'cleaning the house' could be linked to category 'd640 Doing housework' or the activity 'putting socks on' could be linked to category 'd540 Dressing'. Researchers linked twelve out of 527 activities differently from one another and always reached a consensus after discussion. It was not necessary to consult with the third researcher.

Insert table 2. about here

Confirmation of the Comprehensive ICF Core Set for MS: activities and participation
Forty-one out of the 43 second-level categories of participation and activities identified in the present study are included in the Comprehensive ICF Core Set (Table 2). The categories 'd839 Education, other specified and unspecified' and 'd855 Non-remunerative employment' are not included in the Comprehensive ICF Core Set. However, less than one percent of problems in activities and participation were linked to those categories.
When using the method based on interviewing the person with MS in some of the categories only a few problems were coded, for example ' d240 handling stress and other psychological demands', 'd170 basic interpersonal interactions', 'd720 complex interpersonal interactions' although professionals have assessed these problems concerning especially cognition and communication as most frequent. The Comprehensive ICF Core Set includes twelve second- level categories that did not appear in our sample: 'd110 Watching', 'd160 Focusing attention', 'd163 Thinking', 'd175 Solving problems', 'd177 Making decisions', 'd220 Undertaking multiple tasks', 'd330 Speaking', 'd360 Using communication devices and techniques', 'd560 Drinking', 'd830 Higher education', 'd870 Economic self-sufficiency' and 'd930 Religion and spirituality'.

Confirmation of the Brief ICF Core Set for MS: activities and participation
Four out of five second-level categories of the Brief ICF Core Set appeared in our sample: 'd230 Carrying out daily routines', 'd450 Walking', 'd760 Family relationship' and 'd850 Remunerative employment' . The Brief ICF Core Set also includes the category 'd175 Solving problems', which did not emerge in our sample.

Discussion

In this study, we validated the ICF categories of the components of Activities and Participation included in the Comprehensive and Brief Core Set for MS using empirical data from a perspective of persons with MS by asking participants about the most important problems related to activity limitations and participation restrictions. We linked the activities to 43 ICF second-level categories.

The results show that the current list of ICF activities and participation categories from the Comprehensive ICF Core Set for MS can be confirmed almost entirely from a perspective of persons with MS by using the COPM semi-structured interview. Twelve categories of the Comprehensive ICF Core Set did not emerge in the perspectives of participants as the most important activity limitations and participation restrictions in this sample. It is, however, possible to find explanations for why some of the categories did not emerge in our sample. Although distinctions between activities and participation have been studied and some principles recommended [17,18,19] , consensus has not been found regarding the distinctions. The focus of the COPM, occupations that client needs to, wants to or is expected to do, and is unable to perform satisfactorily, is more on participation than on activities. The ICF defines participation as involvement in a life situation and activity as the execution of a task or an action by an individual. For example, if the participant reported that he or she had difficulties in focusing their attention, the researcher asked the participant to talk about a particular activity and/or situation affected by the difficulty. Then participant named life situations such as discussing with friends or reading a fairy tale to children.

Participants in the present sample did not report major problems with communication. Instead of activities which could be linked to category 'd830 Higher education', participants in this sample raised the issue of activities which were linked to the category 'd839 Education, other specified and unspecified', which consists of activities such as studying foreign language as a hobby. The extent of the disability (as measured by EDSS) was severe for over 60% of participants, and 80% of participants receive a disability pension, which might explain why the participants do not prefer such intensive and long-term education and courses.

The participants in our sample reported four out of five Brief ICF Core Set categories of the component activities and participation ('d230 Carrying out daily routines', 'd450 Walking', 'd760 Family relationship' and 'd850 Remunerative employment'). The category 'd175 solving problems' did not appear in the present sample. The most common category in the present sample, 'd920 recreation and leisure', is not included in the Brief ICF Core Set. In previous studies, researchers identified activities linked to the category d920 'recreation and leisure' as highly relevant both from a clinical

perspective [8] and from a perspective of persons with MS [7,20]. The findings of the present study are in line with the findings of previous studies [7,8,20] and support the idea of adding this category to the Brief ICF Core Set for MS.
Our study shows that the subjective experiences of problems encountered in everyday life varied considerably among community-dwelling persons with MS when evaluated using a method that recognizes persons' participation preferences. Hammel et al.[21] also found that persons with disabilities experience participation as a complex and dynamic phenomenon, one which is dependent upon personal choices and environmental influences. Problems participating in everyday activities may vary considerably among persons with MS [22] and may depend on subjective experience [23] . Furthermore, Leonardi et al.[24] have proposed taking the subjective experience of functioning into consideration when defining disability. The results of the present study suggest that the personal variation in the content of possibly perceived problems should be taken into account when using the ICF Core Sets in clinical practice. Moreover, Grill & Stucki [25] remind us that the ICF was not developed as a tool for assessment. Therefore, applying ICF categories directly to clinical practice is questionable.

We used several strategies to verify the trustworthiness of the data analysis. The linking process was performed by two researchers using the guidelines decided upon beforehand. The linking process and the argument for using it were made transparent by using memos. A third researcher was also available to consult with during the linking process. However, there were also limitations in the linking process. Both researchers who linked the problems to the ICF categories were occupational therapists. There is the possibility that other health professionals would have made different decisions. Also, Kappa statistics for agreement [26] could have been used if the judgments would have been made totally independently. However, we chose to use the consensus-making process with rigorous arguments because both researchers were familiar with the data and had discussed it before the linking process.

There are some limitations concerning the context of the study and our ability to make generalizations. First, the characteristics of the present sample are not comparable with a typical sample of persons with MS in all respects. For example, our sample consists of persons with considerable activity limitations (EDSS mean 6), and special inclusion criteria for the study included a restriction on functioning in at least two out of four of the following domains: cognition, mood, fatigue and body control. All of the participants were also motivated to participate in the rehabilitation. Second, the study participants were Finnish residents, which might affect our ability to make generalizations about the results in terms of other cultures and populations. Third, the time of the assessment (late summer) might have had a seasonal effect. However, the

participants also mentioned activities which they did not perform during that season, for example snow clearing or walking on the slippery ground.

This study generated new client-oriented evidence on the ICF Core Sets for MS. The perceived problems of persons with MS support current versions of the ICF Core Sets for MS. The role of recreation and leisure should be taken into consideration when further developing the Brief ICF Core Sets for MS.

Further research is needed to validate the ICF categories for the component Activities and participation included in the Core Sets for MS with a more representative sample of persons with MS. The COPM has not been used before to validate the ICF Core Sets. The perspective of persons with disabilities has been studied using interviews with both an open and ICF-based approach [27,28] and focus groups [29] . Our findings indicate that, in addition to the focus group interviews, the COPM uncovers subjective variations in perceived problems regarding activities and participation. Therefore, it is an appropriate method for revealing the perspective of person with disability. In addition to the COPM, it might be appropriate to use methods which address invisible problems such as psychological well-being and cognition. In the future, in order to better validate ICF Core Sets for MS on a cross-cultural basis, it is important to use methods that reveal the perspective of persons with MS.

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Declarations of interest:
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Figure 1. The ICF and the Chapters of Activities and Participation (d1-d9)

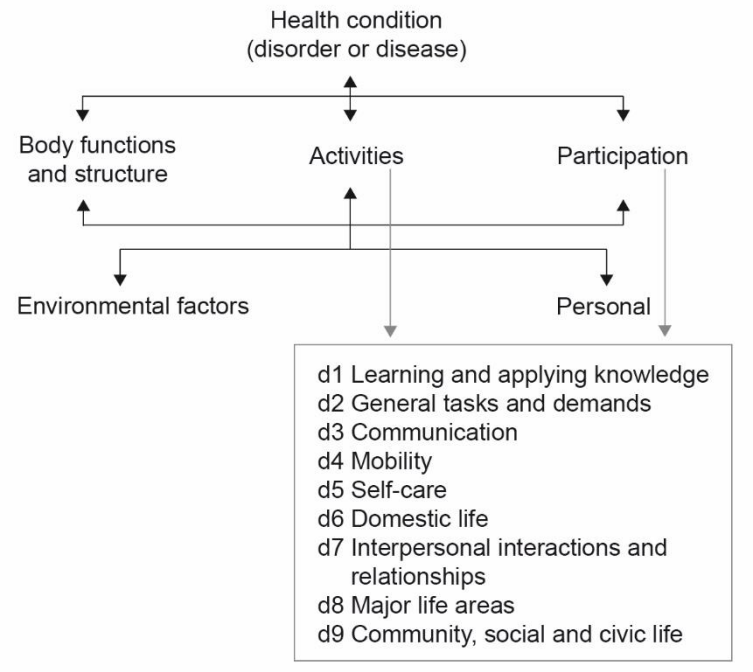

Table1. Characteristics of the Study Participants (n=113)

Mean age yrs (SD/ min–max)	48.4 (8.9 /28–61)
Median duration of disease yrs (min–max)	12 (0–34)
Gender n (%) men women	 34 (30) 79 (70)
Living alone n (%)	37 (33)
Employment status n (%) disability pension student full-time or part-time job unemployed sick-leave	 90 (80) 2 (2) 11 (10) 3 (3) 7 (6)
Disease severity (EDSS) n (%) mean (SD / min–max) moderate 4–5.5 severe 6–8.5	 6 (1.3 / 4–8.5) 43 (38) 70 (62)
Daily functioning (Barthel index) median (min–max)	 18 (0–20)
Disease subtype n (%) relapsing-remitting primary-progressive secondary-progressive unknown	 45 (39.8) 28 (24.8) 37 (32.7) 3 (2.7)

Table 2. Number of most important problems (n=527) in the ICF activities and participation categories reported by participants (n=113)

ICF Code	Category title	Number of problems	%
Chapter 1: Learning and applying knowledge		9	1.7
d155	Acquiring skills [1]	2	0.4
d166	Reading [1]	3	0.6
d170	Writing [1]	4	0.8
Chapter 2: General tasks and demands		21	4.0
d210	Undertaking a single task [1]	6	1.1
d230	Carrying out daily routines [1, 2]	14	2.7
d240	Handling stress and other psychological demands [1]	1	0.2
Chapter 3: Communication		3	0.6
d350	Conversation [1]	3	0.6
Chapter 4: Mobility		134	25.4
d410	Changing basic body position [1]	7	1.3
d415	Maintaining a body position [1]	5	0.9
d420	Transferring oneself [1]	5	0.9
d430	Lifting and carrying objects [1]	19	3.6
d440	Fine hand use [1]	2	0.4
d445	Hand and arm use [1]	7	1.3
d450	**Walking** [1,2]	**23**	**4.4**
d455	Moving around [1]	13	2.5
d460	**Moving around in different locations** [1]	**36**	**6.9**
d465	Moving around using equipments [1]	5	1.0
d470	Using transports [1]	6	1.1
d475	Driving [1]	6	1.1
Chapter 5: Self-care		84	15.9
d510	**Washing oneself** [1]	**28**	**5.3**
d520	Caring for body parts [1]	19	3.6
d530	Toileting [1]	7	1.3
d540	**Dressing** [1]	**23**	**4.4**
d550	Eating [1]	5	0.9
d570	Looking after one's health [1]	2	0.4
Chapter 6: Domestic life		98	18.6
d620	**Acquisition of goods and services**[1]	**22**	**4.2**
d630	**Preparing meals**[1]	**22**	**4.2**
d640	**Doing housework**[1]	**29**	**5.5**
d650	**Caring for household objects**[1]	**24**	**4.6**
d660	Assisting others[1]	1	0.2
Chapter 7: Interpersonal interactions and relationships		12	2.3
d710	Basic interpersonal interactions[1]	1	0.2
d720	Complex interpersonal interactions[1]	1	0.2
d750	Informal social relationships[1]	4	0.8

d760	Family relationship[1,2]	3	0.6
d770	Intimate relationship[1]	3	0.6
Chapter 8: Major life areas		20	3.8
d825	Vocational training[1]	1	0.2
d839	Education, other specified and unspecified	3	0.6
d845	Acquiring, keeping and terminating a job[1]	1	0.2
d850	Remunerative employment[1,2]	9	1.7
d855	Non-remunerative employment	2	0.4
d860	Basic economic self-sufficiency[1]	4	0.8
Chapter 9: Community, social and civic life		146	27.7
d910	Community Life[1]	1	0.2
d920	**Recreation and leisure**[1]	**145**	**27.5**
Total	Most important problems	527	100.0

[1]included in the Comprehensive ICF Core Set

[2] included in the Brief ICF Core Set

n≥20 as bold