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ORIGINAL COMMUNICATION

Characterization of functioning in multiple sclerosis using the ICF

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Abstract The objective of this study was to explore whether it is possible to describe based on the International Classification of Functioning, Disability and Health (ICF) relevant aspects of functioning and disability affected in multiple sclerosis (MS) as well as environmental factors relevant to persons with MS. The specific aim was to identify most relevant 'Body functions', 'Body structures', 'Activities and participation', as well as 'Environmental factors' in patients with MS using the ICF. Additionally, different MS forms were compared with respect to the identified problems. A multi-centre study was conducted in an empirical cross-sectional design. Data from 205 individuals with MS were collected in rehabilitation centres: disease related data, socio-demographic data, single interviews based on the Extended ICF Checklist and a patient questionnaire including ratings on general health and functioning status, Beck Depression Inventory II (BDI-II) and Comorbidity Questionnaire (SCQ). The 129 ICF categories identified represent a comprehensive classification of functioning in MS from the clinical perspective. Differences between MS forms were observed for several ICF categories, EDSS, general health and functioning status, but not for BDI and SCQ. The study showed that it is possible to describe based on the ICF the spectrum in functioning and disability affected in MS as well as environmental factors relevant to persons with MS.

Keywords Multiple sclerosis · Rehabilitation · Relapsing · Remitting · Progressive · Empirical study · Clinical perspective · International Classification of Functioning, Disability and Health (ICF)

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Introduction

Multiple sclerosis (MS) is a chronic, often progressive disease of the central nervous system affecting millions of persons worldwide [37]. MS is associated with physical and psychological disabilities and various functional limitations with significant impact on individual's daily life [16, 18, 34]. Functioning and disability is the core experience of MS persons. Several disease-specific instruments to assess selected aspects of functioning and disability associated with MS are described in literature, e.g. social status [9, 10], quality of life [19], health policy and management [21], prevalence of cognitive dysfunction and effects on daily living activities [1], impact of mood disorders and fatigue [19], psychosocial functioning with chronic pain [23], perceived physical and psychological impact [14] and economic questions like resource consumption, work capacity, health outcome and cost-of-illness (for review see [8]). Besides, being heterogeneous regarding the concepts

included and the precision with which these concepts were defined, these instruments were developed to measure disease consequences and not to assess functioning and health in relation to the disease process, nor to assess the importance of environmental factors. However, functioning and health are not only an outcome, but also the starting point in the assessment of a patient.

Thus, it would be relevant to study to what extent a comprehensive system like the International Classification of Functioning, Disability and Health (ICF) allows a comprehensive description of all aspects of functioning affected in MS or can address the heterogeneity of the problems in functioning that can potentially be affected in MS. The ICF [38] adopted 2001 by the World Health Organization (WHO) relies on a globally accepted framework for classifying problems in functioning and the influence of environmental life context in it.

The ICF with its comprehensive perspective including biological, individual and social aspects of health permits the description of the whole health experience of individuals with MS thereby comparing experiences of different patients in diverse settings and environments [7].

The ICF model identifies three components of the dimension functioning, namely body functions and structures, activities and participation. Dimensions of functioning are both affected by interactions between health conditions and contextual factors (environmental and personal). The components of body functions and structures, activities and participation, and environmental factors (a list of Personal Factors awaits further research and development) are classified based on so called ICF categories.

Linking MS to ICF categories would provide a unified standard language and framework to describe MS-related health [35]. This way facilitates multi- and interdisciplinary management between health professionals and communication between patients and health professionals.

The overall objective of this study was to explore relevant aspects of functioning and disability affected in MS as well as environmental factors relevant to persons with MS based on the ICF. The specific aims of the study were (1) to identify most relevant 'Body functions', 'Body structures', 'Activities and participation', as well as 'Environmental factors' in patients with MS using the ICF and (2) to compare the different MS forms with respect to the identified problems in functioning and 'Environmental factors'.

Materials and methods

Study design

The study was a multi-centre cross-sectional study in two inpatient and two outpatient centres in Switzerland and Germany. The study was approved by the Ethics Committee of St. Gallen (Switzerland), Zurich (Switzerland) and the Ludwig-Maximilian University Munich (Germany) and was conducted based on the principles of the Declaration of Helsinki and the amendment of Somerset West (1996).

Sample

Patients were included, if they (1) met the MS diagnostic criteria of Poser and colleagues [25] or the McDonald criteria [24] for either relapsing-remitting multiple sclerosis (RR MS), primary-progressive multiple sclerosis (PP MS) or secondary-progressive multiple sclerosis (SP MS), (2) were at least 18 years of age, (3) had no mental disorder prior to MS, (4) understood the purpose of the study and (5) signed the informed consent after the whole study were explained to them.

Measures

The health professional collected data based on the so called Extended ICF Checklist forms which are based on the ICF Checklist of the WHO (Version 2.1a) [38].

The ICF Checklist provides a list with 128 first and second level ICF categories of the classification. The ICF classification contains a total of 1424 categories that are mutually exclusive and organized within a hierarchically nested structure with up to four different levels. The ICF categories of the four ICF components 'Body functions' (*b*), 'Body structures' (*s*), 'Activities and participation' (*d*), and 'Environmental factors' (*e*) are denoted by unique alphanumeric codes. An example of the hierarchically nested structure is presented in the following:

- 'b1 Mental functions' (first/chapter level)
- 'b130 Energy and drive functions' (second level)
- 'b1301 Motivation' (third level)

Based on the hierarchically nested structure of the ICF categories, a higher-level category shares the attributes of the lower-level categories to which it belongs, i.e., the use of a higher-level (*b1301 'Motivation'*) category automatically implies that the lower-level category is applicable (*b130 'Energy and drive functions'*).

So called additional categories of the ICF classification which were not part of the original version of the ICF Checklist were added to the ICF Checklist version 2.1a based on information collected from a literature review on health-related quality of life instruments used in studies involving patients with MS. This resulted in the Extended ICF Checklist forms covering a broader spectrum of possible relevant health areas for individuals with MS. With respect to all categories of the ICF, the Extended ICF

Checklist includes 156 ICF categories (123 second level ICF categories from the ICF Checklist, 5 first level ICF categories from the ICF Checklist and 28 additional second level ICF categories). The level of impairment or restriction due to MS is qualified for all components by a qualifier scale (0 = no impairment/restriction to 4 = complete impairment/restriction). For 'Environmental factors' a comparable 0–4 scale is applied, where categories can be either a facilitator or a barrier; a positive sign is added to denote that a category is a facilitator [38]. Socio-demographic data including gender and age, disease related data including MS form, EDSS and comorbidities as well as the current general health and functioning status both scaled from 1 to 10 (1 = no problem to 10 = complete problem) were also collected.

The patients filled in the Beck Depression Inventory II (BDI II) [3, 12], the self-administered Comorbidity Questionnaire (SCQ) [31] as well as the current general health and functioning status in a scale from 1 to 10 (1 = no problem to 10 = complete problem).

Data collection

A convenience sample of patients stratified by MS forms to reflect the distribution of the three different MS forms were recruited in the Department of Neurorehabilitation, Rehabilitation Center, Valens (Switzerland), the Department of Neurology, University Hospital Zurich (Switzerland), the Swiss Multiple Sclerosis Society, Zurich (Switzerland) and the Neurological Rehabilitation Center Quellenhof, Bad Wildbad (Germany).

Data were collected by a physician (LH) based on (1) patient records including disease-specific and socio-demographic data and (2) one-on-one interviews based on the above described Extended ICF Checklist. Whole data collection was carried out in a quiet room lasting approximately 1 h. After the interview, patients were asked whether there were other relevant issues that should have been discussed, and additional issues were documented. Patients filled in all self-reported questionnaires after the one-to-one interview.

Analysis

Descriptive statistics were used to describe the study population. The EDSS score, the general health and functioning status, the BDI score and number of comorbidities based on the SCQ are thereby reported.

To identify the most relevant ICF categories in patients with MS descriptive statistics and a Group Lasso regression [39] using the EDSS and the BDI scores as dependent variables were used. ICF categories of the components 'Body functions', 'Body structures' and 'Activities and participation' that were impaired or restricted (qualified as 1–4) in more than 5% of the patients were reported. In the component 'Environmental factors' ICF categories representing a facilitator or barrier for more than 5% of the patients were also reported. The arbitrary 5% cut-off was applied to facilitate reading of the results section. Group Lasso regression was used for two different reasons: (1) Lasso regression permits the selection of independent variables (ICF categories) in relation of a dependent variable, and (2) Group Lasso regression allows including ordinal variables as independent variables taking their ordinal structure into account. The variables gender, age, time since diagnosis and MS form were forced to remain in the model. ICF categories were not forced to remain in the model. Therefore, ICF categories, which remain in the model, are considered relevant. The best model was selected based on fivefold cross validation [11].

The explorative comparison of the different MS forms for each of the ICF categories were based on 95% confidence intervals (CI 95%) of the percentage values. Whenever the CI-95% of the different MS groups did not overlap, the difference was considered significant. In addition, depending of the distribution of the variables, Kruskal–Wallis test or one-way Anova was used, respectively, to determine whether there were significant differences in the EDSS and the BDI among the different MS groups.

Descriptive data analysis and Group Lasso regression were performed with SAS (9.1) and R version 2.8.1, respectively.

Results

Patient data

From May 2007 to February 2008, 205 patients (57 male (28%) with the mean age at interview of 44.7 years (±12.4)) were recruited in the Valens Rehabilitation Centre ($n = 56$ (27%)), the Neurological Rehabilitation Centre Quellenhof ($n = 52$ (26%)), the Department of Neurology, University Hospital Zurich ($n = 91$ (44%)) and the Swiss Multiple Sclerosis Society ($n = 6$ (3%)). One hundred eight subjects (53%) were outpatients, 97 (47%) inpatients. No patients were excluded from the analysis.

According to the widely used classification based on the BDI score 81 patients (39.5%) have no depression (0–8), 77 patients (37.6%) have slightly to mild depressive symptoms (9–19) and 47 patients (22.9%) have severe to extremely severe depression (20–63). The SCQ revealed back pain in 57 patients (28%), mood related or depressive symptoms in 54 patients (26%), high blood pressure in 27 patients (13%), respiratory disorders in 15 patients (7%) and joint disorders in 12 patients (6%).

Mean general health and functioning status rated by the health professional was 3.5 (2.0 SD) and 3.5 (1.9 SD), respectively. Mean EDSS score of total sample was 3.7 (2.0 SD) (EDSS 1–3.5 in 111 subjects (54%), EDSS 4–6.5 in 78 (38%), EDSS 7–10 in 16 (8%)). Additional selected demographic and disease related data as well as the data of all questionnaires used are listed in Table 1.

More than 5% of patients had problems in 129 (83%) out of the 156 ICF categories of the Extended ICF checklist: 34 in 'Body functions' categories, 13 in 'Body structures' categories, 51 in 'Activities and participation' categories and 31 in 'Environmental factors' categories (see Tables 2, 3).

The beta parameter estimates of the Group Lasso regression for the intercept, age, gender, time since diagnosis and MS form for both, the EDSS and the BDI scores, are presented in Table 4. The ICF categories selected based on the Group Lasso regression using for the EDSS and the BDI, respectively, are presented in the first two columns of Tables 2 and 3. The parameter estimates of the Group Lasso regression show the score changes in the EDSS and BDI, respectively, when comparing PP MS and SP MS to RR MS.

Significant differences between the three MS forms, i.e. comparison between PP MS and RR MS, PP MS and SP MS as well as RR MS and SP MS, are based on CI-95% and indicated in bold. In one-third of the ICF categories of the Extended ICF Checklist ($n = 53$; 34%) significant differences were found regarding the comparison of RR MS and SP MS patients. Comparing RR MS and PP MS patients' significant differences in 16 ICF categories (10%) were identified. With the exception of the two ICF categories *s630 'Structure of reproductive system'* and *e585 'Education and training services, systems and policies'* the other 14 ICF categories also showed significant differences regarding the comparison of RR MS and SP MS. Regarding the comparison of SP MS and PP MS patients, a significant difference was found only in the ICF category *e240 'light'*.

There were significant differences between the three MS forms and general health ($p < 0.0001$) and functioning ($p = 0.0004$) status rated by the health professional as well as the health ($p = 0.0268$) and functioning ($p = 0.0016$) status rated by the patients. There were also significant differences ($p < 0.0001$) in the EDSS regarding the three MS forms. However, no significant differences were found among the different MS groups regarding the BDI score and the number of comorbidities according to the SCQ.

Discussion

Based on ICF, the most relevant 'Body functions', 'Body structures', 'Activities and participation', as well as 'Environmental factors' in MS patients were identified. In addition, differences in functioning and disability as well as 'Environmental factors' with respect to different MS forms could be identified.

In the components 'Body functions' and 'Body structures' 10 ICF categories related to gait and movement manifestations of MS were identified as a problem in more than 50% of the patients (*'Muscle power functions', 'Gait pattern functions', 'Mobility of joint functions', 'Sensations related to muscles and movement functions', 'Muscle tone functions', 'Involuntary movement functions','Psychomotor functions','Spinal cord and related structures', 'Structure of lower extremity'* and *'Structure of upper extremity'*). Similar results have been described in a previous study that addressed the importance of bodily functions from the patient perspective. They found that lower limb function was given the highest priority in both patients with early as well as with longer lasting disease [13]. Four ICF categories related to *'Urination functions', 'Sexual functions', 'Structure of urinary system', 'Structure of reproductive system'* were problems in a high number of patients. This is concordant with previous reported prevalence [22] related to urinary and sexual functions. Corresponding to prior studies concerning the manifestation of

Table 1 Demographic and disease related characteristics of the participants ($N = 205$)

	RR MS ($n = 112$)	SP MS ($n = 60$)	PP MS ($n = 33$)	Total sample ($N = 205$)
N (%)	112 (55)	60 (29)	33 (16)	205 (100)
Age; years, mean (SD)	39.6 (10.6)	52.9 (10.8)	49.7 (12.1)	44.7 (12.4)
Gender; *N* male (%)	23 (11.2)	21 (10.2)	13 (6.3)	57 (27.8)
EDSS; mean (SD)	2.9 (1.7)	5.1 (1.8)	4 (1.9)	3.7 (2.0)
BDI; mean (SD)	12.8 (9.4)	12.5 (7.3)	13.1 (8.4)	12.7 (8.6)
HP GH-status; mean (SD)	2.8 (1.8)	3.9 (2.0)	4.7 (1.8)	3.5 (2.0)
HP F-status; mean (SD)	3.1 (1.9)	3.7 (1.9)	4.0 (1.7)	3.5 (1.9)
P GH-status; mean (SD)	3.9 (2.4)	4.6 (2.2)	5.1 (2.0)	4.4 (2.3)
P F-status; mean (SD)	3.9 (2.6)	4.8 (2.5)	5.4 (1.9)	4.5 (2.5)

RR MS relapsing-remitting multiple sclerosis, *PP MS* primary-progressive multiple sclerosis, *SP MS* secondary-progressive multiple sclerosis, *HP* health professional, *P* patient, *GH-status* general health status, *F*-status functioning status

Table 2 ICF categories referring to 'Body functions', 'Body structures' and 'Activities and participation'

EDSS	BDI	ICF code	ICF titel	1* (*n*)	2* (*n*)	3* (*n*)	4* (*n*)	Sum 1–4 (*n* (%))	RR MS** Sum 1–4 (%)	PP MS** Sum 1–4 (%)	SP MS** Sum 1–4 (%)
Body functions											
		b730	Muscle power functions	38	81	72	3	194 (95)	90	100	100
		b770	Gait pattern functions	46	68	51	19	184 (90)	82	97	100
		b710	Mobility of joint functions	71	76	23		170 (82)	76	91	88
		b620	Urination functions	61	96	9	1	167 (81)	73	88	92
x		b780	Sensations related to muscles and movement functions	44	68	51	4	167 (80)	72	82	95
		b210	Seeing functions	60	80	14		154 (72)	74	67	70
		b130	Energy and drive functions	64	63	19		146 (71)	71	61	77
	x	b134	Sleep functions	69	57	14		140 (68)	67	61	73
	x	b140	Attention functions	74	51	6		131 (64)	57	67	75
x		b735	Muscle tone functions	46	46	34	4	130 (63)	56	48	85
		b280	Sensation of pain	65	41	7		113(49)	45	55	53
		b126	Temperament and personality functions	42	47	9		98 (47)	45	39	57
	x	b765	Involuntary movement functions	38	22	27	1	88 (43)	30	36	70
		b640	Sexual functions	53	24	6		83 (40)	29 †	58	52
		b235	Vestibular functions	46	27	5		78 (38)	41	42	30
	x	b152	Emotional functions	34	30	4		68 (33)	33	27	35
	x	b144	Memory functions	32	16	3		51 (24)	19	27	35
		b515	Digestive functions	32	24			56 (24)	16	24	38
		b530	Weight maintenance functions	23	7	3		33 (16)	11	15	25
		b164	Higher-level cognitive functions	24	8			32 (15)	11	21	25
	x	b550	Thermoregulatory functions	18	12	2		32 (15)	13	12	13
		b535	Sensations associated with the digestive system	17	14	1		32 (14)	6 †	24	23
		b330	Fluency and rhythm of speech functions	19	7			26 (13)	4	12	28
		b320	Articulation functions	14	7			21 (10)	4	15	17
		b525	Defecation functions	13	9			22 (10)	4	9	22
		b114	Orientation functions	15	3			18 (9)	7	9	13
		b117	Intellectual functions	16	3			19 (9)	8	9	15
		b147	Psychomotor functions	14	4	1		19 (9)	5	6	17
		b156	Perceptual functions	18				18 (9)	6	6	17
		b160	Thought functions	18	1			19 (9)	5	3	17
		b167	Mental functions of language	19				19 (9)	6	3	17
		b310	Voice functions	12	4			16 (7)	3	6	15
		b230	Hearing functions	12	2			14 (6)	3	6	13
		b455	Exercise tolerance functions	9	6			15 (6)	4	3	10
Body structures											
		s110	Structure of brain	91	77	36		204 (100)	99	100	100
		s120	Spinal cord and related structures	75	69	46	1	191 (93)	89	94	100
	x	s610	Structure of urinary system	86	70	8		164 (80)	75	82	88
		s750	Structure of lower extremity	61	56	36	1	154 (73)	64	85	82
		s2	Structures of eye, ear and related structures	90	51	9		150 (69)	71	64	70

Table 2 continued

EDSS	BDI	ICF code	ICF titel	1* (*n*)	2* (*n*)	3* (*n*)	4* (*n*)	Sum 1–4 (*n* (%))	RR MS** Sum 1–4 (%)	PP MS** Sum 1–4 (%)	SP MS** Sum 1–4 (%)
	x	s730	Structure of upper extremity	56	56	9		121 (56)	52	58	63
	x	s760	Structure of trunk	40	45	12		97 (42)	31	48	58
		s740	Structure of pelvic region	49	19	1		69 (33)	22	42	47
		s630	Structure of reproductive system	37	13	4		54 (26)	16	48	33
		s720	Structure of shoulder region	36	16	3		55 (25)	24	24	28
		s5	Structures related to the digestive, metabolic and endocrine system	21	30	2		53 (18)	11	21	30
		s710	Structure of head and neck region	17	6			23 (10)	7	3	20
		s3	Structures involved in voice and speech	14	4			18 (9)	4	12	17
Activities and participation											
		d450	Walking	58	64	45	19	186 (91)	84	100	98
		d640	Doing housework	58	88	38	2	186 (91)	85	97	98
		d920	Recreation and leisure	87	71	27		185 (90)	87	88	97
		d455	Moving around	48	47	60	26	181 (88)	81	94	98
x		d620	Acquisition of goods and services	54	93	29	5	181 (88)	79 †	100	98
		d910	Community life	83	62	33		187 (87)	79	97	97
		d230	Carrying out daily routine	67	85	17	1	170 (83)	76	88	93
		d460	Moving around in different locations	47	49	48	20	164 (80)	68	88	98
x		d850	Remunerative employment	43	35	23	52	153 (75)	72	70	82
	x	d445	Hand and arm use	71	52	20	2	145 (71)	59	82	87
		d465	Moving around using equipment	51	67	23	2	143 (70)	56	73	93
		d650	Caring for household objects	46	72	24	1	143 (70)	55 †	82	90
		d166	Reading	88	41	14		143 (69)	65	64	80
		d470	Using transportation	45	51	30	16	142 (69)	57	76	88
	x	d440	Fine hand use	76	41	18	3	138 (67)	56	67	88
		d475	Driving	38	15	13	72	138 (65)	3	73	83
		d660	Assisting others	47	64	17	2	130 (63)	50	73	83
		d430	Lifting and carrying objects	36	57	26	2	121 (59)	45	67	82
		d870	Economic self-sufficiency	74	34	10		118 (58)	55	48	67
	x	d170	Writing	62	39	13	1	115 (56)	46	61	72
x		d630	Preparing meals	61	41	10	1	113 (55)	37†	67	83
		d770	Intimate relationships	83	23	6		112 (54)	46	55	68
		d177	Making decisions	72	26	6		104 (51)	49	42	58
		d830	Higher education	55	29	2		86 (42)	38	33	55
		d220	Undertaking multiple tasks	50	28	6		84 (41)	38	42	47
		d175	Solving problems	42	34	6		82 (40)	38	39	42
		d510	Washing oneself	56	12	5	1	74 (36)	18†	45	65
		d155	Acquiring skills	41	27	1		69 (34)	29	24	47
		d520	Caring for body parts	54	10	5	1	70 (34)	16	36	67
		d530	Toileting	51	14	3	1	69 (34)	14†	39	67
		d865	Complex economic transactions	53	15	1		69 (34)	29	27	45

Table 2 continued

EDSS	BDI	ICF code	ICF titel	1* (*n*)	2* (*n*)	3* (*n*)	4* (*n*)	Sum 1–4 (*n* (%))	RR MS** Sum 1–4 (%)	PP MS** Sum 1–4 (%)	SP MS** Sum 1–4 (%)
		d940	Human rights	23	25	13	1	62 (30)	28	24	38
		d540	Dressing	43	9	4	1	57 (28)	11 †	33	57
		d825	Vocational training	37	19	1		57 (28)	29	15	33
		d570	Looking after ones health	32	9	1		42 (20)	11	30	33
		d930	Religion and spirituality	9	16	15		40 (20)	15	21	27
		d760	Family relationships	29	10	1		40 (19)	16	24	22
		d720	Complex interpersonal interactions	28	8			36 (18)	14	18	23
		d730	Relating with strangers	27	5			32 (16)	9	18	27
		d740	Formal relationships	22	9			31 (15)	9	12	28
		d550	Eating	16	4	2		22 (11)	5	15	18
	x	d210	Undertaking a single task	20				20 (10)	10	9	10
		d330	Speaking	14	5	1		20 (10)	4	15	17
		d560	Drinking	15	3	3		21 (10)	5	12	18
		d163	Thinking	19				19 (9)	7	6	15
		d350	Conversation	15	1			16 (8)	4	6	17
		d860	Basic economic transactions	12	3	1		16 (8)	5	6	13
		d750	Informal social relationships	12	1			13 (6)	0	9	17
		d420	Transferring oneself	8	2			10 (5)	5	3	5
		d710	Basic interpersonal interactions	7	3			10 (5)	2	9	8
x		d110	Watching	4	4	2		10 (5)	2	12	7

Selected based on the Group Lasso regression using for the EDSS and the BDI (first and second columns) and reported as at least mildly impaired by more than 5% of patients, ordered by frequency (*n*). Table presents the proportional distribution (%) of identified categories for the total sample and separately for the three MS forms (last three columns)

**1* mild impairment/restriction, *2* moderate impairment/restriction, *3* severe impairment/restriction, *4* complete impairment/restriction

***RR MS* relapsing-remitting multiple sclerosis, *PP MS* primary-progressive multiple sclerosis, *SP MS* secondary-progressive multiple sclerosis

† Significant difference between RR MS and SP MS as well as RR MS and PP MS; no difference between SP MS and PP MS

cognitive and psychological symptoms [13, 26, 30] due to MS, eight ICF categories were related to *'Attention functions'*, *'Temperament and personality functions'*, *'Emotional functions'*, *'Memory functions'*, *'Higher-level cognitive functions'*, *'Intellectual functions'*,*'Thought functions'* and *'Mental functions of language'*. The high prevalence of cognitive impairments associated with MS has been previously observed in up to over 50% in all MS subtypes, especially in patients with longer lasting disease course [13]. Concordant with prior reports on the impact of MS on vitality [20, 27], the ICF categories *'Energy and drive functions'* and *'Sleep functions'*, were reported as impaired by about 70% of patients.

In the component 'Activities and participation', as described in prior studies on social functioning and participation in social activities [18, 19], *'Recreation and leisure'*, *'Community life'*, *'Remunerative employment'*, and *'Intimate relationships'* were frequently reported to be restricted. Related to these findings, it has been reported that informal use of health and community care was highly correlated with disease severity, and was further influenced by healthcare systems and family structure [18]. It has been reported that, independently of the physical disability degree, impaired functioning and participation in social activities can have major influences on role limitations in work and social life [1].

Moreover, it is notable that all but two of the ICF categories of the component 'Environmental factors' were reported as a barrier or a facilitator. Remarkably, patients quantified them more often as a facilitator than as a barrier. The most frequently reported barrier was *'climate'*. The most frequently reported facilitators were *'Immediate family'*, *'Extended family'*, *'Friends'*, and *'Health professionals'*. These results are in accordance with reports confirming the importance of social support for functional ability [6] and indicate the types of environmental parameters that could be considered in MS patients.

The results reporting the percentage of patients who had a problem in the different ICF categories were consistent with the results of the Group Lasso regression. All but two of the ICF categories remaining in the model using the EDSS as dependent variable were a problem for more than

Table 3 ICF categories referring to 'Environmental factors': selected based on the Group Lasso regression using for the EDSS and the BDI (first and second columns) and reported as at least mildly impaired by more than 5% of patients, ordered by frequency (*n*)

EDSS	BDI	ICF code	ICF titel	Barrier 1–4* (*n*)	Facilitator +1–+4* (*n*)	Sum 1–4 (*n* (%))	RR MS** Sum 1–4 (%)	PP MS** Sum 1–4 (%)	SP MS** Sum 1–4 (%)
Environmental factors									
	x	e310	Immediate family	7	198	205 (100)	100	100	100
	x	e410	Individual attitudes of immediate family members	6	199	205 (100)	100	100	100
	x	e415	Individual attitudes of extended family members	14	189	203 (99)	100	94	100
	x	e315	Extended family	15	184	199 (97)	97	94	98
		e320	Friends	24	174	198 (97)	97	94	97
		e420	Individual attitudes of friends	14	185	199 (97)	99	91	97
		e325	Acquaintances, peers, colleagues, neighbours and community members	47	121	168 (82)	76	91	88
		e450	Individual attitudes of health professionals	2	149	151 (74)	67	82	82
		e355	Health professionals	3	140	143 (70)	61	79	82
	x	e225	Climate	114	28	142 (69)	67	55	82
		e580	Health services, systems and policies	2	131	133 (65)	54	64	87
		e110	Products or substances for personal consumption	24	102	126 (61)	54	61	75
x		e120	Products and technology for personal indoor and outdoor mobility and transportation		125	125 (61)	43†	73	88
		e240	Light	65	57	122 (60)	61	36	70
		e590	Labour and employment services, systems and policies	45	62	107 (52)	55	42	52
	x	e465	Social norms, practices and ideologies	64	31	95 (46)	46	33	53
		e155	Design, construction and building products and technology of buildings for private use	4	82	86 (42)	21†	61	70
		e150	Design, construction and building products and technology of buildings for public use	6	72	78 (38)	20†	52	65
		e330	People in positions of authority	19	58	77 (38)	33	36	47
		e525	Housing services, systems and policies	2	74	76 (37)	21†	48	62
	x	e575	General social support services, systems and policies	8	68	76 (37)	34	27	48
	x	e250	Sound	54	18	72 (35)	32	24	47
		e570	Social security services, systems and policies	7	63	70 (34)	32	33	38
		e540	Transportation services, systems and policies	1	61	62 (30)	14†	45	52
		e440	Individual attitudes of personal care providers and personal assistants	3	50	53 (26)	13	30	48
		e585	Education and training services, systems and policies	20	31	51 (25)	33	9	18
		e340	Personal care providers and personal assistants	1	47	48 (23)	10†	30	45
		e360	Other professionals		41	41 (20)	12	30	30
		e455	Individual attitudes of health-related professionals		40	40 (20)	13	27	28
		e115	Products and technology for personal use in daily living		24	24 (12)	5	12	23
		e550	Legal services, systems and policies	2	14	16 (8)	7	6	10

Table presents the proportional distribution (%) of identified categories for the total sample and separately for the three MS forms (last three columns)

**1* mild barrier/facilitator, *2* moderate barrier/facilitator, *3* severe barrier/facilitator, *4* complete barrier/facilitator

***RR MS* relapsing-remitting multiple sclerosis, *PP MS* primary-progressive multiple sclerosis, *SP MS* secondary-progressive multiple sclerosis

† Significant difference between RR MS and SP MS as well as RR MS and PP MS; no difference between SP MS and PP MS

Table 4 The parameter estimates of the Group Lasso regression for the intercept, age, gender, time since diagnosis and MS form for both, the EDSS and the BDI scores

	EDSS Beta parameter estimates	BDI Beta parameter estimates
Intercept	0.5522	8.4426
Age	0.0228	0.0069
Gender	0.2813	−0.6332
Time since diagnosis	−0.0004	−0.1692
PP MS	−0.0051	1.0154
SP MS	0.5561	−0.3109

PP MS primary-progressive multiple sclerosis, *SP MS* secondary-progressive multiple sclerosis

50% of the patients. The ICF category *d110 'Watching'* was also selected as independent variables even though a low percentage of patients presented a problem in this 'Activities and participation' domain. The statistical selection of *d110 'Watching'* is consistent with the impairments in seeing functions associated with MS frequently reported in the literature [e.g. [13]].

Also the ICF categories identified based on the Group Lasso regression analysis including the BDI score were areas of functioning and disability frequently impaired and restricted in patients with MS. It does not come to a surprise that different mental functions, such as sleep, attention and memory were highly related to the level of depression. These results suggest that the problems in these mental functions which are characteristic for MS were not only purely associated to this condition but also to the frequent comorbidity depression. This interplay of cognitive, affective and functional changes in MS has already been suggested in other investigations [32] and should be further studied in the future.

An additional interesting result related to the ICF categories selected using the BDI as independent variable is the fact that eight different environmental factors were selected based on this methodology. This emphasizes the importance of not only the social but also the physical environment in the functioning of the patients with MS, especially in the area of psychological functioning.

Comparison of the three MS forms, i.e. comparison between PP MS and RR MS, PP MS and SP MS as well as RR MS and SP MS, revealed several significant differences in the identified ICF categories between the three MS forms. Remarkably, 129 (84%) of 156 ICF categories show that patients with SP MS have more frequently problems and limitations compared to patients with RR MS or PP MS. Overall most significant differences are found by comparison between RR MS and SP MS. This could be explained by the fact that individuals with RR MS experience generally less longer lasting limitations in functioning, at least in their early stages, compared to individuals with SP MS who experience increasing limitations in functioning over the disease time course. Notably, the high frequency of significant difference in the component 'Activities and participation' reflects the higher level of limitations in patients with SP MS within this aspect of life. Further, our results support previous data that most common symptoms in RR MS are visual and sensory disturbances in comparison to PP MS in which gait disorders and pareses are most prevalent [17, 29]. Overall, our findings of the significant differences between SP MS compared to RR MS may imply that these two MS forms manifest different limitations and restrictions in the course of the disease. Although we could not detect significant differences between SP MS compared to PP MS, we could still descriptively observe that patients with SP MS presented a higher number of limitations in functioning than patients with PP MS. This has also been demonstrated in previous studies related to clinical course, additional demographic and imaging features indicating differences in underlying pathogeneses [1, 33].

Similar significant differences in EDSS between the three MS forms found have been reported previously where mean EDSS was 3, 2.75 in RR MS, 3.5 in PP MS and 4.0 in SP MS [28, 29]. These EDSS differences emphasize how different the MS forms are with respect to functioning and participation.

Overall rating by the health professional regarding the general health and functioning status was higher than the same rating by the patients. This may be because the health professional making the rating had opportunity to compare all patients with each other, while patients only focused on their own status.

Patients showed a wide range of BDI scores from zero to 56 points, while the mean of all patients was 12.7 BDI points in line with other studies [2, 5]. In general, BDI scores between 10 and 19 indicate mild to moderate depression [4]. In addition the SCQ confirmed the high prevalence of mood related and depressive symptoms reported by patients with MS [15]. However, there were no significant differences between the BDI score and the MS forms. This is in contrast to previous studies reporting differences in BDI between MS forms, such as higher BDI scores for SP MS compared to the other MS forms [26, 36].

Some issues should be considered when interpreting these results. First, a convenience sampling procedure combined with a stratified sampling procedure was used. Therefore, the results of the study may not be representative. In addition, the lack of very severe cases (EDSS over 8) has to be taken into account. This is related to the centres involved in the study, which were rehabilitation centres and an outpatient clinic. Future studies need to address this issue by including different health and care institutions. Furthermore, this patient group was recruited based on the

average distribution on the MS form. This resulted in a large number of patients with RR MS, but a lower number of patients with SP MS and PP MS. Future studies should aim to include equal numbers of patients per diagnoses and especially focus on PP MS, which obtained the lowest number in this study. Although only one interviewer was involved in this study, the way the interviews were conducted might have influenced the results. Another limitation of this study refers to the comparison among the different MS forms. Since this comparison is explorative, the results reporting those differences have to be interpreted with caution and only considered for further generation of hypothesis and not for confirmatory purposes. Last, this study represents a Swiss and German perspective. Therefore, other results could be found in other cultures, especially with respect to 'Environmental factors'.

Conclusion

This empirical study described aspects in functioning and disability affected in MS as well as 'Environmental factors' relevant to persons with MS based on the ICF. Further, the comparison between three different MS forms with respect to the problems in functioning and disability as well as 'Environmental factors' revealed significant differences.

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