chronic illness

Functioning and disability in multiple sclerosis from the patient perspective

Michaela Coenen,[1,2] Birgit Basedow-Rajwich,[3] Nicolaus König,[3] Jürg Kesselring[4] and Alarcos Cieza[1,2]

Abstract

Multiple sclerosis (MS) has a great impact on functioning and disability. The perspective of those who experience the health problem has to be taken into account to obtain an in-depth understanding of functioning and disability. The objective was to describe the areas of functioning and disability and relevant contextual factors in MS from the patient perspective. A qualitative study using focus group methodology was performed. The sample size was determined by saturation. The focus groups were digitally recorded and transcribed verbatim. The meaning condensation procedure was used for data analysis. Identified concepts were linked to International Classification of Functioning, Disability and Health (ICF) categories according to established linking rules. Six focus groups with a total of 27 participants were performed. In total, 1327 concepts were identified and linked to 106 ICF categories of the ICF components Body Functions, Activities and Participation and Environmental Factors. This qualitative study reports on the impact of MS on functioning and disability from the patient perspective. The participants in this study provided information about all physical aspects and areas of daily life affected by the disease, as well as the environmental factors influencing their lives.

[3]Kempfenhausen Centre for Treatment of Multiple Sclerosis, Marianne-Strauß-Klinik, Berg, Germany
[4]Department of Neurorehabilitation, Valens Rehabilitation Centre, Valens, Switzerland

[1]Institute for Health and Rehabilitation Sciences, Research Unit for Biopsychosocial Health, Ludwig-Maximilians-University (LMU), Munich, Germany
[2]ICF Research Branch in cooperation with the WHO Collaborating Centre for the Family of International Classifications in Germany (at DIMDI)

Corresponding author:
Alarcos Cieza, Institute for Health and Rehabilitation Sciences, Research Unit for Biopsychosocial Health, Ludwig-Maximilians-University, Marchioninistr. 17, 81377 Munich, Germany
Email: Alarcos.Cieza@med.lmu.de

Introduction

Multiple sclerosis (MS) affects around 2.5 million people worldwide and is one of the most common neurological disorders and causes of disability among young adults. Symptoms of MS can vary widely over time in a given individual and also from individual to individual and is unpredictable in terms of prognosis. Some people with MS experience little disability during their lifetime, but up to 60% are no longer fully ambulatory 20 years after onset. This has significant implications for the performance of activities of daily living, participation in social life,[1] quality of life[2] and cost to society.[3] An in-depth understanding of the impact of MS on disability and functioning is the basis for the optimal management of MS with its various symptoms.

One important way to obtain information when analysing the impact of the disease on functioning and disability is to ask those who experience the health problem. Qualitative methods constitute the most appropriate methodology. They are increasingly being taken into account when focusing on the patient perspective. One of the most broadly applied techniques in qualitative health research is the focus group methodology.[4]

Up to now, few studies have evaluated focus groups consisting of individuals with MS. The majority of such studies focused on the perception of the health condition, as well as patients' adjustment to it, like the experience of being diagnosed with MS,[5] communication with health professionals,[6] coping with MS,[7] adjustment to the disease[8] and perception of needs.[9] There are only three studies which explore specific functional decrements and problems important to individuals with MS, namely Douglas and colleagues'.[10] study focusing on the perception of pain along with Prutny and colleagues'.[11] and Rubin's[12] studies exploring gender-specific aspects, such as motherhood,

pregnancy and sexuality. Studies highlighting limitations in activities and restrictions in participation from the patient perspective are missing. Another topic reported in qualitative studies using focus groups is the evaluation of patient-education programmes from the patient perspective.[13-15] However, focus group studies dealing with health-service provision and policy from the perspective of those who experience the disease don't exist.

Studies using other methodologies, like quantitative analyses and Delphi exercises, also aim to study the importance of body functions, limitations in activities and relevant aspects of the environment from the patient perspective.[16-19] All studies mentioned above, whether they use qualitative or quantitative methodologies, did not report on functioning and disability from a comprehensive perspective that emphasizes the interaction of impairments with limitations in everyday life and the positive or negative influences of environmental factors. None of these studies reflected how different the lives of persons with MS can become in light of a supportive or hindering physical, social and attitudinal environment. The importance of such a comprehensive view has become increasingly important over the last 20 years.

The introduction of the International Classification of Functioning, Disability and Health (ICF)[20] has definitely contributed to providing a more comprehensive view. The ICF is the current World Health Organization's (WHO) framework for describing and assessing functioning and disability based on a bio-psycho-social perspective. It offers an etiologically neutral framework and classification to describe the different determinants of health and health-related domains of functioning and disability. With the ICF, clinicians can now rely on a common and shared terminology that complements the ICD-10 to report the experiences of persons with health conditions in

general and MS in particular. The ICF can be used as a common basis for health communication between patients and health professionals, and among health professionals. It contains not only impairments but also day-to-day experiences of disability that individuals with MS have to face during the course of the disease.[21,22]

In the ICF, functioning and disability are understood as the result of the interaction between the health condition and contextual factors. This interaction comprises the ICF components *Body Functions, Body Structures, Activities and Participation* and the contextual factors *Environmental* and *Personal Factors* (Figure 1). The units of the classification – the ICF categories – are arranged hierarchically in these components. These categories are divided into chapters, which constitute the first level of precision. Categories at higher levels (e.g. second or third level) are more detailed. In total, the ICF classification contains 1424 ICF categories, each allotted to the named components of the classification with the exception of the component *Personal Factors*, which has not yet been classified. Each ICF category is denoted by a code composed of a letter that refers to the respective component of the classification (b: *Body Functions*; s: *Body Structures*; d: *Activities and Participation* and e: *Environmental Factors*) and is followed by a numeric code starting with the chapter number (one digit), followed by the second level (two digits) and the third and fourth levels (one digit each) (Figure 1).

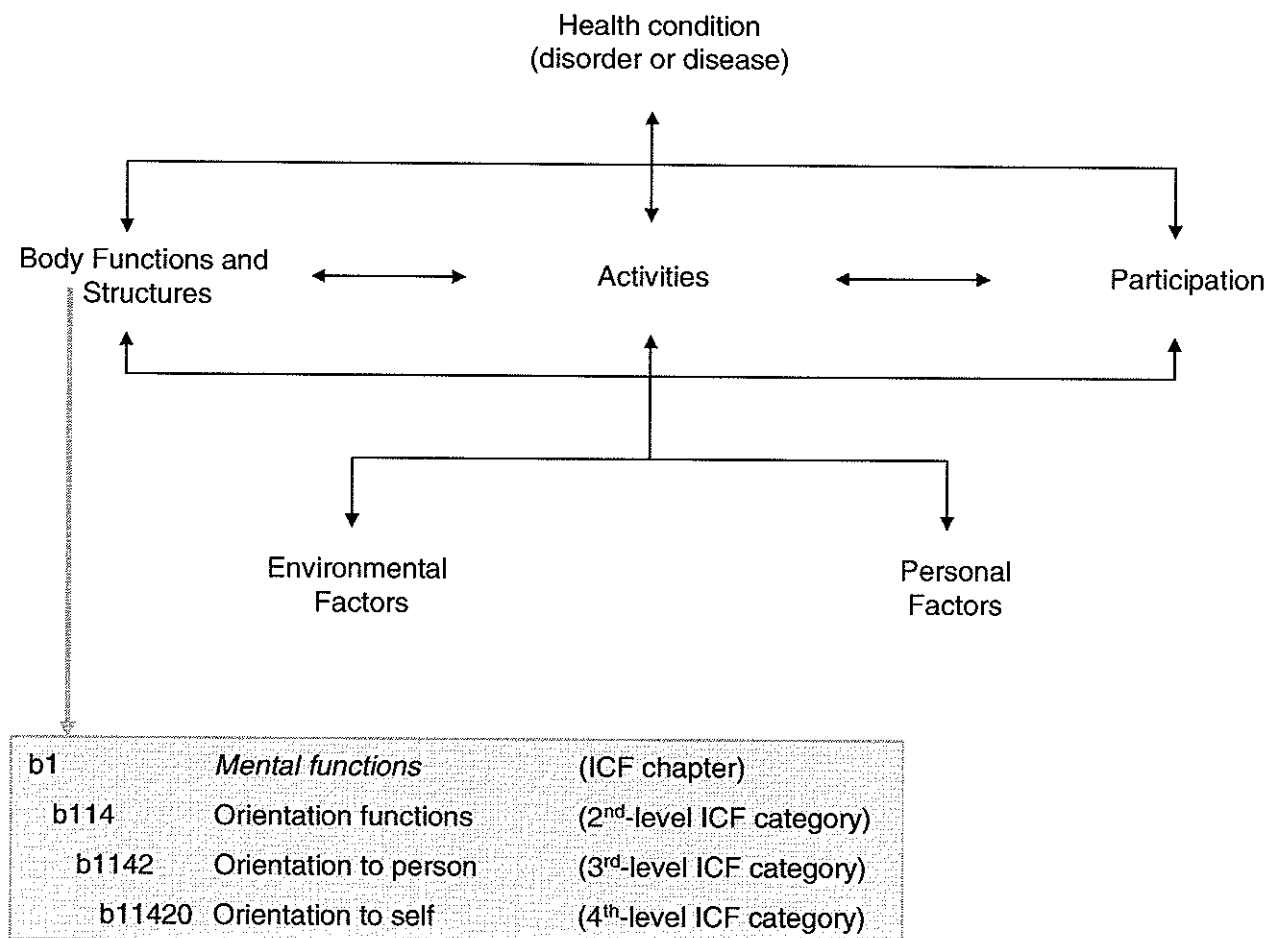| b1 | *Mental functions* | (ICF chapter) |
b114	Orientation functions	(2nd-level ICF category)
b1142	Orientation to person	(3rd-level ICF category)
b11420	Orientation to self	(4th-level ICF category)

Figure 1. The biopsychosocial perspective and the ICF classification.

Beside the fact that the component *Personal Factors* have not yet been classified, another weakness of the ICF classification is its comprehensiveness. The classification with its 1424 ICF categories is hardly applicable in clinical practice. To tailor the classification to specific health conditions (e.g. MS), agreed-on lists of ICF categories – ICF Core Sets – were developed allowing clinicians and researchers to classify and describe functioning using the widely accepted terminology of the ICF.[23,24] In addition, as has been shown in previous (qualitative) studies, the ICF can be a useful tool in structuring the collection and analysis of data in qualitative research.[25–27] Using the ICF as a framework can facilitate the comparison of the results of qualitative studies with those of quantitative studies (sometimes called mixed-methodology research).

The objective of this study is to describe the areas of functioning and disability and relevant contextual factors in MS from the patient perspective. The specific aim is to identify areas of functioning and disability, as well as environmental and personal factors, important to individuals with MS using the ICF as a framework.

Methods

Design

A focus group study was performed using the ICF as a framework to identify areas of functioning and disability, as well as environmental and personal factors, from the patient perspective.

Focus groups are a 'carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment' (p. 5).[28] They are especially useful for studies that involve complex issues that entail many levels of feeling and experience. The non-directive nature of focus groups affords participants an opportunity to comment, explain, disagree and share experiences and attitudes.[29]

The study was approved by the Ethics Committee of the Ludwig-Maximilians-University (LMU) in Munich (Germany).

Participants

Individuals were included if: (1) they had definite MS according to the McDonald criteria,[30,31] (2) they were at least 18 years old, (3) they had a score of at least 26 in the Mini-Mental Status Examination (MMSE),[32] (4) the purpose of the study was understood and (5) an informed consent was signed. Subjects diagnosed with mental disorders prior to the onset of MS were excluded.

The purposeful sampling of participants followed the maximum variation strategy[33] based on three criteria: gender, age and disease severity assessed by the Expanded Disability Status Scale (EDSS).[34] These criteria ensured that men and women with a broad range in disease severity and from different age groups were included in this study to provide a comprehensive and diverse description of functioning and disability in MS.

Patients who participated in the study gave written informed consent according to the Declaration of Helsinki, 1996.

Sample size

Based on our experiences from previous studies using focus group methodology,[25,35] the focus group size was set at a maximum of seven persons because of the complexity of the topic and to represent different opinions and facilitate interactions. Thus, each participant had a greater opportunity to talk, which is reported to be an important aspect for group dynamics in groups with ill participants.[36] The overall sample size – defined as the number of focus groups performed – was determined by saturation.[33]

Saturation refers to the point at which an investigator has obtained sufficient information from the field (see data analysis: saturation of data).

Materials

A topic guide developed in a previous study[25] describing how to prepare and perform the focus group sessions using pre-defined, open-ended questions was applied. The following open-ended questions reflecting the components of the ICF classification were asked:

(1) If you think about your body and mind, what does not work the way it is supposed to? (*Body Functions*)
(2) If you think about your body, in which parts do you have problems? (*Body Structures*)
(3) If you think about your daily life, what are your problems? (*Activities and Participation*)
(4) If you think about your environment and your living conditions, what do you find helpful or supportive? (*Environmental Factors* – facilitators)
(5) If you think about your environment and your living conditions, what barriers do you experience? (*Environmental Factors* – barriers)
(6) If you think about yourself, what is important about you and the way you handle your disease? (*Personal Factors*)

Data collection

The focus groups were led by a moderator and one group assistant at the Kempfenhausen Treatment Centre for MS (Germany). The moderator of the focus groups (MC) was a psychologist with expertise in conducting group processes. At the beginning of each focus group, the procedure of the session was explained, and the

model of the ICF was presented in layman terms to all participants. The open-ended questions were presented to the participants visually by a Power-Point presentation. An oral summary of the main results was given back to the group at the end of each focus group session. This enabled the participants to add aspects not mentioned previously in the session. The assistant observed the process within the group. S/he also filled in descriptive field notes to document verbal and non-verbal topics mentioned during the session. After each focus group, a debriefing with moderator and assistant took place to review the course of the session. The focus groups were digitally recorded and transcribed verbatim.

Data analysis

The data analysis conducted in this study followed a two-step procedure consisting of a qualitative analysis and a linking procedure to the ICF.

Qualitative analysis. The meaning condensation procedure[37] was used for qualitative data analysis. In the first step, the transcripts of the focus group sessions were read through to get an overview of the collected data. Then the data were divided into meaning units, and the theme that dominated a meaning unit was determined. A meaning unit was defined as a specific unit of text containing either a few words or a few sentences with a common theme.[38] Therefore, a meaning unit division did not follow linguistic grammatical rules; the text was divided where the researcher discerned a shift in meaning. In the third step, the concepts contained in the meaning units were identified (Table 1). A meaning unit could contain more than one concept.

Linking to the ICF. To report the identified concepts in a systematic way and to obtain an overview of the areas of functioning and disability experienced by individuals with MS from a comprehensive perspective,

Table 1. Procedure of data analysis

Transcription Meaning unit	Concept Qualitative analysis	ICF category Linking procedure
Moderator: If you think about your *daily life, what are your* *problems?*		
A: Fifteen years ago I stopped driving a car. My reaction time is really reduced, and some- times I have problems seeing.	Driving a car Reduced reaction time Problems seeing	d4751 Driving nc b210 Seeing functions
B: For me, driving a car is asso- ciated with autonomy or dependency. I have to rely on my wife. So I have to ask, "Could you please take me?"	(In)Dependence due to car driving Reliance on wife	nd e310 Immediate family

these concepts were presented using the ICF classification. The concepts identified in the qualitative analysis were linked to ICF categories based on established linking rules[39,40] in a systematic and standardized way (Table 1). According to these linking rules, health professionals trained in the ICF and the linking rules are advised to link each concept to the ICF category representing this concept most precisely. One concept could be linked to one or more ICF catego-ries, depending on the content of the con-cept. If a concept was too general to allow a decision on the linking to an ICF compo-nent, chapter or category, the statement was considered as 'not defined' (nd) (e.g. 'prob-lems with activities'). If a concept described an aspect which was not covered by the ICF, the code 'not covered' (nc) was attributed (e.g. 'the illness isn't visible for others'). Concepts identified as 'Personal Factors' (e.g. 'showing others one's physical prob-lems openly') were documented as 'pf'.

Saturation of data

Saturation of data was defined as the point during data collection and analysis at which the linking of the identified concepts of two consecutive focus groups each revealing less than 10% new second-level ICF categories compared to the number of second-level ICF categories which were identified in the respective previous focus group.[27,41] In this study, saturation of data was reached after performing six focus groups (Figure 2).

Accuracy of the analysis

To ensure the accuracy of data analysis, two strategies were conducted: First, *multiple coding*, which refers to the qualitative anal-ysis and the linking procedure of the first focus group by two health professionals, was performed. The two health profes-sionals compared their identified concepts of the qualitative analysis and the linked ICF categories in a structured discussion to reach agreement. The results of their discus-sion were documented. Second, *peer review*, which refers to analysing and linking random samples of 15% of the transcribed text and 15% of the identified concepts (of the first health professional), was carried out by a second health professional. The degree of agreement between the two health pro-fessionals regarding the linked ICF catego-ries was calculated by kappa statistic with 95%-bootstrapped confidence intervals (95%CI).[42,43] The values of the kappa
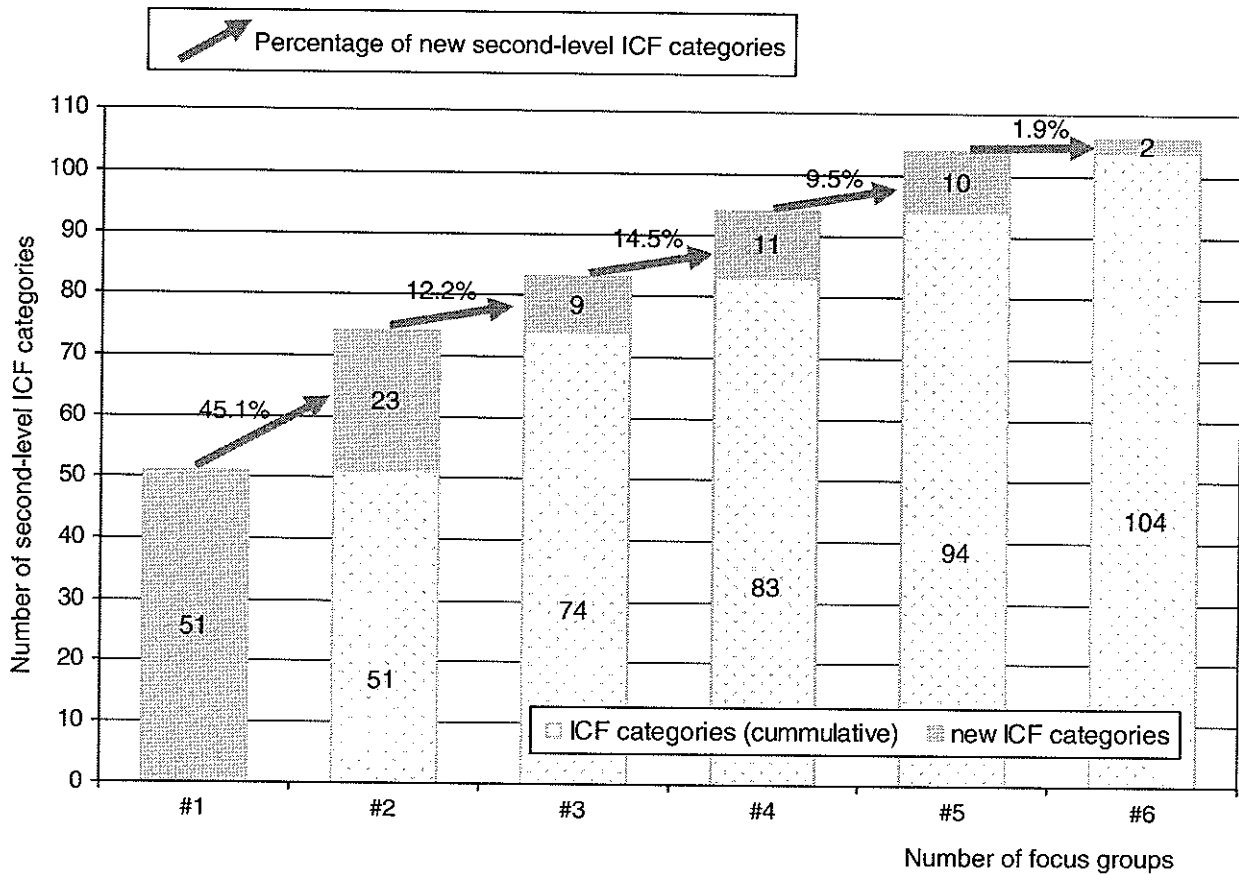
Figure 2. Saturation of the qualitative data in the focus groups.

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 Kappa analysis was performed with SAS for Windows V9.1 (SAS Institute Inc., Cary, NC, USA). In this study, the kappa coefficient for the agreement between the two investigators was 0.56 [0.45; 0.67].

Results

Description of the focus groups and participants

A total of 27 participants were assigned to six focus groups. The focus group sessions lasted from 41 min to 1 h 31 min (mean 63 min) including a short break. Participants' characteristics are summarized in Table 2.

Qualitative analysis and linking

In total, 1327 concepts were identified in the transcripts of the six focus groups. These concepts were linked to 171 ICF categories. For 84 of the 171 categories, which were at the third and fourth level of the classification, the corresponding second-level categories were considered for further data analysis. Thus, the concepts were linked to a total of 106 second-level categories (35 *Body Functions* categories, 33 *Activities & Participation* categories and 38 *Environmental Factors* categories).

It is important to note that when participants were asked about affected body parts, they did not report body structures as such, but the corresponding impaired body functions. Thus, no body structures were identified in this study. The clearest example is the

Table 2. Characteristics of participants (N = 27)

Characteristics of participants (N = 27)	
Age [years]; Median (range)	50 (28–73)
Gender; n female/male	19/8
Living alone; n	8
Employment status; n	
Paid employment/self-employed	7
Homemaker	3
Unemployed (for health reasons)	3
Pensioned/(early) retired	14
MS form; n	
RR MS	11
PP MS	5
SP MS	11
Disease duration (based on date of diagnosis) [years]; Median (range)	13 (1–48)
EDSS; Median (range)	6.0 (2.5–8.0)
BDI sum score; Median (range)	12.5 (1–31)

RR MS: Relapsing-Remitting MS; PP MS: Primary-Progressive MS; SP MS: Secondary-Progressive MS; EDSS: Expanded Disability Status Scale; BDI: Beck Depression Inventory.

structure of the brain. The participants of the study did not mention any structural changes in the structure of the brain but all problems in the mental functions (e.g. problems in memory and attention functions). Sixty concepts were too unspecific to be linked to ICF categories and were assigned 'not defined' (nd). In addition, several concepts (n = 155) have not yet been classified by the ICF and were linked to 'not covered' (nc). Two-hundred forty-eight concepts were assigned to 'personal factors' (pf).

The results of this study reaffirm the complexity and multidimensionality of the daily lives of individuals with MS. The spectrum of problems in functioning associated with the health condition and contextual factors was identified. All chapters of the ICF components *Body Functions, Activities and Participation and Environmental Factors* were identified by linking the concepts retrieved from the qualitative analyses of the participants' statements (Tables 3–5).

Two *Body Functions* categories were identified in all focus groups (Table 3),

namely *b152 Emotional functions* and *b620 Urination functions*. Participants in the study highlighted the complexity of these *Body Functions* categories:

A: 'I am often very disappointed with my body because it doesn't do what I want it to do.'

B: 'What's aggravating are primitive functions, like bladder functions. A simple function, like using the rest room, planning to use the restroom and then one can't urinate. And seven minutes later you have to urinate, although you don't want to and you get in a hectic rush because you can't find a restroom.'

In addition, the ICF categories *b130 Energy and drive, b140 Attention functions* and *b144 Memory functions* from the chapter *b1 Mental functions* were identified in five of the six focus groups. Other frequently linked *Body Functions* categories referred to *b210 Seeing functions* and *b455 Exercise tolerance functions,* respectively. Focusing on these impaired body functions, the participants in the study described their interactions with

Table 3. *Body Functions* (b): Number of focus groups in which ICF categories at the second level of classification were identified from the patient perspective

ICF code	ICF category title	Reported in focus groups; *n*
Chapter 1: Mental functions		
b126	Temperament and personality functions	2
b130	Energy and drive functions	5
b140	Attention functions	5
b144	Memory functions	5
b147	Psychomotor functions	I
b152	Emotional functions	6
b156	Perceptual functions	I
b160	Thought functions	3
b180	Experience of self and time functions	I
Chapter 2: Sensory functions and pain		
b210	Seeing functions	5
b220	Sensations associated with the eye and adjoining structures	I
b230	Hearing functions	3
b235	Vestibular functions	3
b265	Touch function	3
b270	Sensory functions related to temperature and other stimuli	2
b280	Sensation of pain	2
Chapter 3: Voice and speech function		
b320	Articulation functions	2
b330	Fluency and rhythm of speech functions	I
Chapter 4: Functions of the cardiovascular, haematological, immunological and respiratory systems		
b440	Respiration functions	I
b455	Exercise tolerance functions	5
b460	Sensations associated with cardiovascular and respiratory functions	I
Chapter 5: Functions of the digestive, metabolic and endocrine systems		
b510	Ingestion functions	I
b525	Defecation functions	3
b535	Sensations associated with the digestive system	I
Chapter 6: Genitourinary and reproductive functions		
b620	Urination functions	6
b630	Sensations associated with urinary functions	I
b640	Sexual functions	I
Chapter 7: Neuromusculoskeletal and movement-related functions		
b730	Muscle power functions	3
b735	Muscle tone functions	3
b760	Control of voluntary movement functions	3
b765	Involuntary movement functions	2
b770	Gait pattern functions	3
b780	Sensations related to muscles and movement functions	3
Chapter 8: Functions of the skin and related structures		
b840	Sensation related to the skin	I
b850	Functions of hair	I

Table 4. *Activities and Participation (d)*: Number of focus groups in which ICF categories at the second level of classification were identified from the patient perspective

ICF code	ICF category title	Reported in focus groups; *n*
Chapter 1: Learning and applying knowledge		
d166	Reading	2
d170	Writing	1
d177	Making decisions	1
Chapter 2: General tasks and demands		
d210	Undertaking a single task	1
d220	Undertaking multiple tasks	2
d230	Carrying out daily routine	4
Chapter 3: Communication		
d330	Speaking	1
Chapter 4: Mobility		
d410	Changing basic body position	3
d415	Maintaining a body position	2
d430	Lifting and carrying objects	2
d440	Fine hand use	3
d445	Hand and arm use	2
d450	Walking	6
d455	Moving around	4
d460	Moving around in different locations	2
d465	Moving around using equipment	3
d470	Using transportation	1
d475	Driving	2
Chapter 5: Self-care		
d510	Washing oneself	4
d530	Toileting	3
d540	Dressing	2
d550	Eating	1
d560	Drinking	1
d570	Looking after one's health	1
Chapter 6: Domestic life		
d620	Acquisition of goods and services	2
d630	Preparing meals	3
d640	Doing housework	3
Chapter 7: Interpersonal interactions and relationships		
d730	Relating with strangers	1
d770	Intimate relationships	1
Chapter 8: Major life areas		
d845	Acquiring, keeping and terminating a job	2
d850	Remunerative employment	3
Chapter 9: Community, social and civic life		
d920	Recreation and leisure	6
d940	Human rights	1

Table 5. *Environmental Factors* (e): Number of focus groups in which ICF categories at the second level of classification were identified from the patient perspective

ICF code	ICF category title	Reported in focus groups; n
Chapter 1: Products and technology		
e110	Products or substances for personal consumption	5
e115	Products and technology for personal use in daily living	3
e120	Products and technology for personal indoor and outdoor mobility and transportation	5
e125	Products and technology for communication	4
e135	Products and technology for employment	1
e150	Design, construction and building products and technology of buildings for public use	5
e155	Design, construction and building products and technology of buildings for private use	5
e160	Products and technology of land development	4
e165	Assets	1
Chapter 2: Natural environment and human-made changes to environment		
e225	Climate	2
Chapter 3: Support and relationships		
e310	Immediate family	6
e315	Extended family	3
e320	Friends	4
e325	Acquaintances, peers, colleagues, neighbours and community members	4
e330	People in positions of authority	2
e340	Personal care providers and personal assistants	1
e345	Strangers	2
e350	Domesticated animals	1
e355	Health professionals	3
e360	Other professionals	2
Chapter 4: Attitudes		
e410	Individual attitudes of immediate family members	3
e415	Individual attitudes of extended family members	3
e420	Individual attitudes of friends	3
e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	3
e430	Individual attitudes of people in positions of authority	1
e435	Individual attitudes of people in subordinate positions	1
e445	Individual attitudes of strangers	2
e455	Individual attitudes of health-related professionals	2
e460	Societal attitudes	4
Chapter 5: Services, systems and policies		
e515	Architecture and construction services, systems and policies	2
e520	Open space planning services, systems and policies	1
e525	Housing services, systems and policies	2
e530	Utilities services, systems and policies	1

(continued)

Table 5. Continued

ICF code	ICF category title	Reported in focus groups; n
e540	Transportation services, systems and policies	2
e555	Associations and organizational services, systems and policies	4
e565	Economic services, systems and policies	1
e570	Social security services, systems and policies	2
e580	Health services, systems and policies	6

activities of daily living, like *d166 Reading, d450 Walking* and the environmental factor *e445 Attitudes of others*:

> C: 'With my eyes, the problem is that I do have the time, but I can't read for very long. Because I have this oscillating view of things, going back and forth. That's irritating, when you want to read and the letters always move around. That's a problem which really bothers me. Otherwise I could do something else with my time.'
> D: 'I think exhaustion is also one of the main things. I mean things that go well when I'm not exhausted, like walking... as soon as I'm a bit exhausted – for example when I go swimming – afterwards, I can hardly walk to the shower room without someone stopping me and commenting, 'Already drunk today?'

One participant of our focus groups clearly reported on the relationship of fatigue, cognitive functions, limited activities and restricted participation:

> A: 'I cannot concentrate as I did before due to fatigue. By the way, this is my major problem. It is just a large problem at my job. In the past I worked full time, followed by a 75-percent job. And now – now I work only half-time.'

From the component *Activities and Participation d450 Walking* and *d920 Recreation and leisure* emerged as the most relevant topics for the participants. The quotation of one of the study's participants

listed below shows the impact of the health condition on leisure activities and social relationships:

> E: 'My friend says, 'Let's go to the theatre together,' and that's a nice idea. But I can't accept her offer. I don't know how I'll be doing the next three days.'

Other frequently identified *Activities and Participation* ICF categories refer to *d230 Carrying out daily routine* and *d510 Washing oneself*, respectively:

> F: 'Well, doing several things at the same time, that doesn't always work – setting priorities, coordinating things.'
> G: 'I now have one of those shower stools, then it's alright (showering). Because I can't stand in the bathtub and shower – I'd fall down.'

In this example, one individual participating in the focus groups clearly described the interaction of everyday activities (*d510 Washing oneself*, *d415 Maintaining a body position*) and environmental factors (*e115 Products and technology for personal use in daily living, e155 Design, construction and building products and technology of buildings for private use*).

Regarding the ICF component *Environmental Factors*, *e310 Immediate family* and *e580 Health services, systems and policies* emerged as the most relevant topics for the participants in the focus groups. A participant of the focus groups

reported on the interaction of the environmental factors *e310 Immediate family* and *e410 Individual attitudes of immediate family members* and the body function *b152 Emotional functions,* as well as personal factors as follows:

> G: 'He (her husband) gives me everything. Well, he helps me, he supports me, and sometimes he lets me flip out and says, 'Go ahead and flip out, I'll leave now and when I come back, you'll be fine.' He gives me the right to sometimes be mad at myself.'

Several ICF categories were frequently identified from the patient perspective in the first *Environmental Factors* chapter *e1 Products and technologies*: *e110 Products or substances for personal consumption, e120 Products and technology for personal indoor and outdoor mobility and transportation, e150 Design, construction and building products and technology of buildings for public use* and *e155 Design, construction and building products and technology of buildings for private use*:

> H: 'When you go out to eat or want to go out to eat, you have to plan ahead of time, 'Um, are the restrooms in the basement?' – No! Then it's (the restaurant) no good, because you can't get down.'

The quotation of this participant illustrates the interaction between the environmental factors (*e150 Design, construction and building products and technology of buildings for public use*) and activities of daily living (*d920 Recreation and leisure, d450 Walking* and *d455 Moving around*).

Many experiences which mainly focus on how to the cope with the disease and relate to *Personal Factors* were identified from the patient perspective. Concepts which were too unspecific to be linked to ICF categories and coded as 'nd' were, for example, 'problems with legs' or 'problems with daily activities'. Concepts identified in the transcripts of the focus group sessions which were coded as not covered by the ICF ('nc') include aspects like 'needing more time to accomplish daily activities,' 'performing activities overhead' or 'meaningful use of leisure time.'

Discussion

This study identified a wide range of areas of functioning and disability, as well as environmental and personal factors, from the patient perspective. The results of this study offer an overview of the impact of MS on functioning and disability. Areas of functioning and disability and environmental factors are presented using ICF categories to report the retrieved data in a systematic and comprehensive way. The results of this study reaffirm the complexity and multi-dimensionality of the daily lives of individuals with MS and that functioning and disability can only be understood in light of environmental and personal factors. The ICF was a useful tool to guide the participants of the focus groups to think about their lives in a comprehensive way and to perform the analyses of the huge amount of data produced. As has been shown in this study, the presentation of the results could also be structured based on the ICF.

All chapters of the ICF components *Body Functions, Activities and Participation* and *Environmental Factors* were represented by the ICF categories identified by the linking of the participants' statements to the ICF. Most areas of functioning and disability and environmental factors were reported in at least two out of six focus groups. However, from these results it cannot be concluded that those areas are equally relevant for all individuals with MS or equally frequent. The number of focus groups in which specific areas associated with body functions, activities of daily living, participation and environmental factors came up may provide a rough impression about the potential relevance of these areas. It is essential to

take into account the qualitative methodology used in this study aimed to identify areas of functioning and disability, as well as relevant contextual factors. Determining the frequency of these issues requires further investigation using quantitative methods.

Our study illustrates that numerous body functions are relevant from the patient perspective and confirms the findings of several cross-sectional studies in MS patients using the ICF framework for data analysis. The main issues were fatigue and energy and drive functions, muscle power, muscle tone, muscle endurance functions, sensation of pain, bladder and bowel problems, sexual problems, visual problems and impaired memory functions.[19,44,45]

Some *Body Functions* categories require detailed discussion. The participants reported a wide range of emotions, like depressive symptoms, anxiety or anger which are covered by the ICF category *b152 Emotional functions*. In addition, several categories of the chapter *b1 Mental functions* (e.g. *b130 Energy and drive, b140 Attention functions, b144 Memory functions*) were frequently identified from the patient perspective. This highlights the relevance of the 'invisible' MS symptoms which were also reported in other studies as highly relevant from the patient perspective.[18,46] In our study, even patients with a mild disease course reported problems with cognitive functions, as well as impaired emotional functions, which can result in an enormous emotional burden and a reduction of quality of life as stated in the literature.[47–50] In addition, impaired cognitive functions are associated with depressive mood, low self-esteem and self-efficacy,[51,52] as well as restricted social functioning[13] and less successful coping.[53,54] Impaired emotional functions (e.g. anxiety) were found to be associated with increased risk of MS relapses[55] and poor quality of life.[56]

Besides problems in mental functions, impairments in *b210 Seeing functions* and

b620 Urination functions were frequently reported from the patient perspective. These *Body Functions* categories refer to main functional problems among persons with MS. Both are reported in Heesen and colleagues' study as being highly important to MS patients.[18] Although bladder problems are often seen as a taboo to be talked about or asked about by healthcare professionals, the focus group participants talked about these problems in a very detailed way and demonstrated the enormous consequences and burden imposed by their bladder problems. It is known that bladder problems, as well as sexual and bowel problems, are common in MS patients[57] and are highly associated with reduced quality of life[58,59] even in early stages of MS.[60] However, only the participants of one focus group stated that they had problems with sexual and/or bowel functions. The participants of the other focus groups were probably not willing to talk about these sensitive topics to avoid embarrassment.

ICF categories of all chapters were identified from the patient perspective in the ICF component *Activities and Participation*. This reflects the broad spectrum of limited activities and restricted participation which usually occurs in persons with MS. The ICF categories *d450 Walking* and *d920 Recreation and leisure* were identified as the most relevant topics from the patient perspective. This finding is supported by Khan and Pallant's study, which identified both topics as highly prevalent in their sample of 101 Australian MS patients.[45] In line with Heesen and colleagues, walking seemed to be one of the core activities which could be interpreted as a substitute for perceived independence or autonomy from the perspective of MS patients.[18] An ICF-based study on the prediction of patient-reported performance in the component *Activities and Participation* identified walking capacity (measured as speed and walking distance), besides fine hand use and changing and

maintaining body position as the most significant predictor for difficulties in the performance of activities of daily living, such as self-care, mobility and domestic life.[19] Recently published reviews confirm that even patients with low disability levels place a high emphasis on mobility, the loss of which contributes to a substantial burden in MS patients.[61,62] Furthermore, limitations in walking are associated with poor quality of life, reduced activities of daily living and a loss of productivity.[61,62]

The most relevant topics for the participants in the focus groups were *e310 Immediate family* and *e580 Health services, systems and policies* in the ICF component *Environmental Factors*. One should be aware that both categories were reported as barriers and as facilitators. This result supports the importance of the family relationship and support received from family members, as well as the availability of health services and treatment options. Several studies reported on the association between family behaviour and patients' physical disability and functioning;[63,64] social support was reported as being one of the most important issues associated with adaptation and adjustment to MS[65,66] and quality of life of MS patients.[67,68] Furthermore, Lerdal and colleagues reported that social functioning was the only factor with a significant relationship to perceived MS severity among all aspects of quality of life or personal factors.[69] Regarding the category *Health services, systems and policies,* the relevance of our findings is supported by Khan and Pallant, who stated that this ICF category is one of the main environmental factors from the perspective of Australian individuals with MS.[45] When exploring the perceived needs, the majority of MS patients reported a need for rehabilitation, psychosocial support or counselling.[70]

The large number of identified ICF categories assigned to the first chapter of the *Environmental Factors* component *e1*

Products and technologies shows that many environmental aspects can be relevant facilitators or barriers for individuals with MS. The category *e110 Products or substances for personal consumption* includes, amongst others, the third-level category *e1101 Drugs,* which was ambiguously discussed by the participants in this study. Although disease-modifying drugs were perceived as facilitators influencing the disease course positively, the patients reported several unpleasant side effects of medication. Other categories in the first *Environmental Factors* chapter frequently linked to the participants' statements were *e120 Products and technology for personal indoor and outdoor mobility and transportation,* *e150 Design, construction and building products and technology of buildings for public use* and *e155 Design, construction and building products and technology of buildings for private use.* The identification of the mobility and transportation category underlines the relevance of transportation services and means of transportation to MS patients.[70] The participants in the focus groups frequently referred to their difficulties entering public and private buildings due to their functional limitations. Heavy doors, unergonomically designed handles, door thresholds, stairs or lack of elevators and public bathrooms located in the basement were described as barriers in their environment.

Even though the *Personal Factors* component has not yet been classified by the ICF, experiences related to personal factors are of interest because most of them identified in this study referred to coping strategies. Keeping a positive attitude, being optimistic and accepting the disease were frequently identified as a way to positively influence one's life after having been diagnosed with MS. However, some patients reported their dissatisfaction in coping with the disease and finding new activities or goals to achieve; they struggled with the definition of a 'new' meaning of life and their

modified social roles. Nevertheless, priority in the focus groups was given to the positive attitudes toward the disease. The relevance of this finding is supported by studies which investigated the meaning of 'hope' in the process of coping with MS or the influence of personal factors, like attitude, coping and self-efficacy on quality of life and adjustment to MS.[65,66,71–74]

Several concepts identified from the patient perspective were labelled as 'not covered' by the ICF. It is important to emphasize that the majority of these concepts does not refer to aspects of functioning and disability as defined by the ICF classification. These concepts mainly cover time-related or disease-specific aspects (e.g. 'needing more time to accomplish daily activities' and 'the illness isn't visible for others') and general quality of life or satisfaction with life, respectively. Since the ICF does not cover these aspects nor quality of life in the sense of subjective well-being,[75] these issues could not be linked to the ICF. However, other 'not covered' concepts identified in this study are clearly related to functioning and disability as defined by the ICF (e.g. 'performing activities overhead'). These issues should be included in the update process of the ICF, which has already been initiated by WHO.

Limitations of the study

There are also some limitations of this study that should be mentioned. First, the sample consisted of German MS patients. To establish a cross-cultural perspective, we suggest that our method should be used in similar studies in other countries. Second, patients were recruited in one MS rehabilitation centre. Including MS patients of other settings may produce different results. However, patients with a wide range of functional impairments defined by the EDSS participated in this study.

It is important to admit that having the ICF in mind may affect the results of analyses of transcripts in qualitative research. The researchers of this study know the ICF very well. Therefore, they used a very 'ICF-framed' language when identifying the concepts in the transcripts of the focus group sessions. Other researchers might have identified different concepts. Future studies could be performed to answer this question. The linking process was performed by two health professionals according to established linking rules.[39,40] However, it remains unclear whether other health professionals would have decided differently. In addition, when using these linking rules one must remember that there are several details that cannot be expressed when simply using ICF categories (e.g. 'eating and drinking in public places,' 'using cutlery in restaurants' and 'daily fluctuations in fatigue'). The verbatim transcripts showed that participants provided relevant information about the complex relationship between functioning and disability and contextual factors. Further in-depth qualitative analysis of these focus groups could be performed to have a closer look at the experiences of persons with MS to generate hypotheses for future research.

Finally, we performed six focus groups following the strategy of saturation of data with the criteria of two consecutive focus groups each revealing less than 10% additional second-level ICF categories in relation to the number of second-level ICF categories identified in the respective previous focus group. Participants in a seventh focus group might still report new themes not yet addressed. It is important to mention that several strategies were used to improve and verify the trustworthiness of data analysis. (1) *Triangulation* ensured the comprehensiveness of data. We accomplished *investigator triangulation* by using two health professionals to perform the data

analysis (multiple coding).[76,77] (2) *Reflexivity* was assured by filling in field notes and performing a debriefing after completing each focus group session. (3) *Clear exposition* was assured by establishing guidelines for performing the focus groups (including open-ended questions), verbatim transcription and linking rules.[39,40] (4) Finally, *peer review* was practiced, as described earlier. The kappa coefficient of 0.56 for the accuracy of the peer review is comparable with other qualitative studies using the linking rules.[25,27]

Conclusion

In conclusion, this study investigates the impact of MS on functioning and disability from the patient perspective. A wide range of areas of functioning and disability, as well as environmental and personal factors were identified using the ICF as a framework. The individuals participating in this qualitative study provided information about all aspects of their bodies and areas of daily life affected by the disease, as well as environmental factors that positively or negatively influenced their lives. These data retrieved from the patient perspective provide a basis for developing international standards for comprehensively describing functioning and disability in individuals with MS.

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Conflict of interest

The authors declare that there is no conflict of interest.

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