

ORIGINAL REPORT

USE OF INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF) TO DESCRIBE PATIENT-REPORTED DISABILITY IN MULTIPLE SCLEROSIS AND IDENTIFICATION OF RELEVANT ENVIRONMENTAL FACTORS

Fary Khan, RACP¹ and Julie F. Pallant, PhD²

From the ¹Department of Rehabilitation Medicine, University of Melbourne Neurological Rehabilitation Physician – Royal Melbourne Hospital Melbourne and ²Faculty of Life and Social Sciences, Swinburne University of Technology, Melbourne, Hawthorn, Australia

Objective: To use the International Classification of Functioning, Disability and Health (ICF) to describe patient-reported disability in multiple sclerosis and identify relevant environmental factors.

Methods: Cross-sectional survey of 101 participants in the community. Their multiple sclerosis-related problems were linked with ICF categories (second level) using a checklist, consensus between health professionals and the “linking rules”. The impact of multiple sclerosis on health areas corresponding to 48 ICF categories was also assessed.

Results: A total of 170 ICF categories were identified (mean age 49 years, 72 were female). Average number of problems reported was 18. The categories include 48 (42%) for body function, 16 (34%) body structure, 68 (58%) activities and participation and 38 (51%) for environmental factors. Extreme impact in health areas corresponding to ICF categories for activities and participation were reported for mobility, work, everyday home activities, community and social activities. While those for the environmental factors (barriers) included products for mobility, attitudes of extended family, restriction accessing social security and health resources.

Conclusion: This study is a first step in the use of the ICF in persons with multiple sclerosis and towards development of the ICF Core set for multiple sclerosis from a broader international perspective.

Key words: ICF, disability, multiple sclerosis, outcome assessment.

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Correspondence address: Fary Khan, Department of Rehabilitation Medicine, University of Melbourne, Neurological Rehabilitation Physician – Royal Melbourne Hospital, Poplar Road Parkville, Melbourne VIC 3052, Australia.
E-mail: fary.khan@mh.org.au

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INTRODUCTION

Multiple sclerosis (MS) is a chronic, often progressive, disease of the central nervous system. Its worldwide prevalence is estimated as 1–2.5 million cases (1). There are approximately 15,000 persons with MS in Australia (2) and it is the third

leading cause of disability in adults between 20 and 50 years of age (3).

The demyelinating lesions in MS can produce disability and functional limitation with significant impact on the everyday life of persons with MS and their caregivers. The symptoms are varied and include fatigue, visual, motor and sensory deficits, bladder and bowel impairment, cognitive dysfunction and pain (4). Rehabilitation is an effective element in the overall management of MS (1, 5) and can minimize limitation in activity and restriction in participation (6, 7).

Environmental factors make up the physical, social and attitudinal environment in which people live their lives. These are external to the person, but interact with health conditions at all levels (body structure and function, everyday activities and participation in society) (8). These factors are common to all people (disabled or not), and interact with individual health conditions in unique ways to produce different disability outcomes (9). These physical, attitudinal and policy barriers can impact on activity and restrict participation in a person with MS, and need to be identified. The adaptation of the environment could then meet the unique needs of people with MS.

The International Classification of Functioning, Disability and Health (ICF) provides a framework of disability and functioning with different perspectives of health from a biological, individual and social perspective (8). ICF checklists have been used to identify patient problems in chronic conditions and in acute hospitals (10, 11). The concepts within health status measures have been linked with ICF categories using linking rules (12). Furthermore, core sets have been developed for many conditions (e.g. stroke) (13), for use in clinical studies and to guide multidisciplinary assessments. No studies in MS have used the ICF framework to describe patient disability. It is important to link the ICF categories with the perspective and experience of the person living with MS in terms of their reported limitation in activity and restriction in participation.

The objective of this study was to link patient-reported disability in an MS community cohort with ICF categories using a checklist and to identify relevant environmental factors. A further aim was to assess the impact of MS on specific health areas corresponding to ICF categories. The results of this study provide information regarding relevant health areas for persons

with MS and these may serve to introduce the Australian perspective to the development of the ICF core sets for MS.

METHODS

Participants and setting

This study included a cross-sectional survey of persons residing in the community with a confirmed diagnosis of MS. These participants were identified from the MS database at the Royal Melbourne Hospital (RMH), a tertiary referral centre in Victoria, Australia. Persons on this database were recruited through the Multiple Sclerosis Society of Victoria, public and private neurology clinics across Victoria. All participants in this database were reviewed by a neurologist who confirmed diagnosis using diagnostic criteria (14, 15), the stage of MS (relapsing remitting, secondary or primary progressive, and relapsing remitting secondary progressive (overlapping) stage), and severity of disease using Expanded Disability Status Scale (EDSS) (16).

Participants selected for this study needed to reliably report the main problems in living with MS. They were between 18 and 65 years of age, with a confirmed diagnosis of MS, residing in the community (area of greater Melbourne <60 km radius), who had known limitations in their neurological status (including mobility) and EDSS scores between 2 and 7.5 and cognition (Kurtze Functional System (KFS) score between 0 and 2) (16). Participants with severe cognition deficits (KFS greater than 2), and those who were institutionalized and/or bedbound were excluded.

This study was approved by the University of Melbourne and the RMH, Human Research and Ethics Committees.

Data collection

At the time of recruitment 204 (20%) of 1023 patients listed on the RMH MS Database were eligible for this study due to entry criteria (Fig. 1). All were invited by post to participate in the study and the 101 who consented were recruited for the project. All interviews were conducted by trained research assistants and physicians who participated in 3 half-day structured ICF workshops at RMH. This involved education about the model and core ICF principles, and practical application of the ICF checklist.

Measures

Each participant was interviewed using a structured format and asked to nominate a list of the problems affecting their everyday life due to MS (available from authors). There was no prompting or use of MS problem lists. The information provided was checked and clarified with the patient medical record, RMH database and where possible with carers. Any discrepancies were resolved with discussion (with the participant) and consensus agreement between reviewers. Each problem was then linked with the ICF checklist of 170 second-level categories from the 362 second-level categories of the whole ICF classification system. This checklist incorporated the 125 categories in the World Health Organization (WHO) checklist (17) and another 45 added ICF categories that linked with participant answers (available from authors). With regards to all categories in the second level of the ICF, this checklist included 48 (42%) categories from the component body function, 16 (34%) from body structure, 68 (58%) from activities and participation and 38 (51%) from environmental factors.

Each participant then reviewed a checklist comprising 48 ICF categories (all levels of classification) for the 2 components of ICF categories "activities and participation" and "environmental factors". Participants were asked whether MS had an impact in the health areas described in the corresponding ICF categories (available from authors). They rated areas of significant impact for them using a 6-point scale: 1=no impact (0%), 2=minimal (1–4%), 3=mild (5–24%), 4=moderate (25–49%), 5=severe (50–95%) and 6=extreme impact (96–100%). These correspond with the percentages for WHO ICF qualifiers 0–4 (8). We used the 6-point impact scale for improved responsiveness and sensitivity to describe the range of impact reported by participants

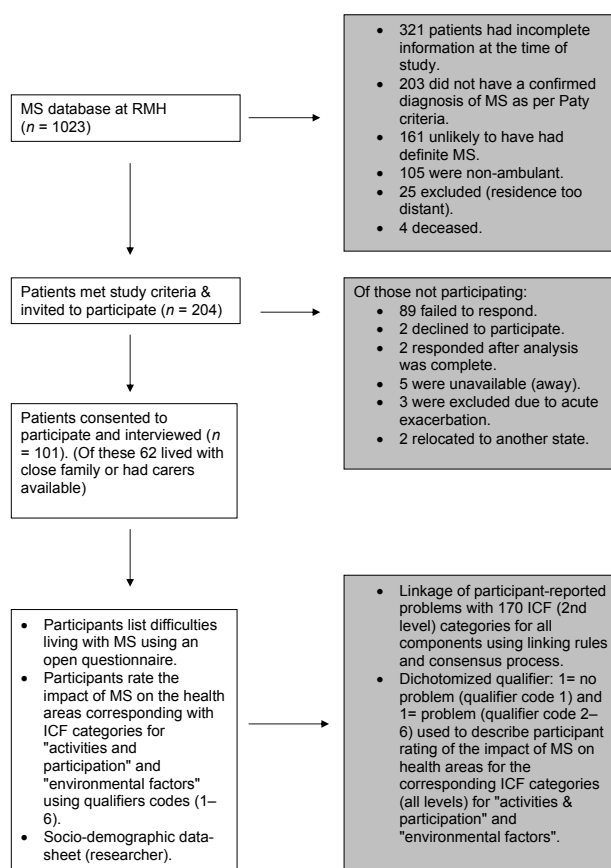


Fig. 1. Recruitment process. MS: multiple sclerosis; RMH: Royal Melbourne Hospital; ICF: International Classification of Functioning, Disability and Health.

for health areas in corresponding ICF categories, and to accommodate the fluctuating nature, paroxysmal symptoms and complexity of MS. Barriers (hindrances) were identified as a major influence on a persons' ability to engage in activity, participation and good health practices. Impact was defined as subjectively perceived costs inherent in undertaking activity, participation and health behaviours.

Authors trained in ICF used the linking rules (12) to match each problem reported by the participant with an appropriate code from the ICF categories (second level). All problems pertaining to personal factors currently not coded within the ICF were grouped under "personal factors" (18). Consensus between health professionals was used to decide which categories should be linked to each answer. After data extraction, both reviewers compared their results. As in the report by Weigl et al. (19), any disagreements concerning selected categories and codes were resolved by a trained third health professional.

Information relating to participant socio-demographic and disease status was collated using a standard data form.

Statistical methods

Descriptive analysis was used to describe the study population. The frequency of participant-reported problems was linked with the ICF categories (second level). The stage of disease for participants corresponding with each ICF category was also reported.

We used a dichotomized qualifier: 0=no problem (qualifier code 1) and 1=problem (qualifier code 2–6) to describe participant rating of the impact of MS on 48 health areas for the corresponding ICF categories. The frequency of participants who reported limitation in the categories for the component "activities and participation" are presented. For

Table I. Characteristics of participants with multiple sclerosis

Characteristic	Average/frequency
Age, years (mean (SD), range)	49.50 (9.19), 28–64
Male	49.56 (9.11), 28–64
Female	49.38 (9.56), 29–61
Sex (n, %)	
Male	29 (28.7)
Female	72 (71.3)
Living (n, %)	
Alone	24 (23.8)
Family	71 (70.3)
Other	6 (5.9)
Working (n, %)	
Retired/unemployed	60 (59.4)
Working full-time (36 hours/week)	35 (34.7)
Working part-time (20 hours/week)	6 (5.9)
Pension (n, %)	
No	47 (46.5)
Yes	54 (53.5)

With permission from Lippincott, Williams and Wilkins. F. Khan, T McPhail, C. Brand, L. Turner-Stokes, T. Kilpatrick. Multiple sclerosis: disability profile and quality of life in an Australian community cohort. *Int J Rehabil Res.* 2006; 29: 87–96.

environmental factors, the frequencies of persons reporting a specific category as a barrier are reported.

If the patient repeatedly assigned one ICF category, it was counted once only to avoid bias. Consensus opinion was used if there was a discrepancy in the MS-related problem listed by the participant and their carer. Carer report was included in the information used to link ICF categories for problems listed by the person with MS. All data was entered twice to avoid errors on data entry. SPSS 11.0 for Windows was used for analysis.

RESULTS

The socio-demographic and disease characteristics of the 101 participants with MS are shown in Table I. The number of problems reported by the participants with MS ranged from 8 to 30 (mean 18). Twenty-six carers reported at least 2 additional problems compared with participant report (to be presented in a separate paper). There was 100% agreement between reviewers for linkage of participant-reported problems with the ICF categories.

Tables II–V show the frequency of limitations in categories reported by at least one-third (33%) of the participants (for each category), linked with the ICF categories for all 4 components: “body function”, “body structure”, “activities and participation” and “environmental factors”. The frequency and participant disease stage for each category is also presented.

A total of 170 ICF categories were identified. In the component “body function”, 10 categories each were selected for mental function, and neuromuscular and movement-related functions, sensory function and pain (6 categories each) and genitourinary functions (5 categories). At least 90% of participants reported limitations in at least one of the categories of the chapters: mental function (b1), function of cardiovascular system (b4), genitourinary and reproductive function (b6), neuromuscular and movement related functions (b7).

In the component “body structure”, 93 (92%) participants reported structure of genitourinary system (s6).

All 9 chapters of the “activities and participation” component had limitations and included 68 categories. The main areas linked: mobility (11 categories), learning and applying knowledge (10 categories), and major life areas such as employment (9 categories), and interpersonal relationships (7 categories).

Table II. Frequency of limitation in the linked categories for the component body function reported by at least one-third (33%) of the participants with multiple sclerosis (n=101)

ICF Code	ICF Code description	Total number of participants linked responses n (%)	Number of participant and stage of disease			
			RR	SP	PP	rr-SP
b130	Energy and drive functions	98 (97.0)	51	26	14	7
b134	Sleep	84 (83.1)	47	21	11	5
b140	Attention	66 (65.3)	37	17	9	3
b144	Memory	62 (61.3)	37	16	4	5
b152	Emotional functions	97 (96.0)	50	26	14	7
b210	Seeing	47 (46.5)	24	16	4	3
b235	Vestibular (incl. Balance functions)	71 (70.3)	34	19	13	5
b265	Touch*	34 (33.6)	15	10	7	2
b280	Sensation of pain	76 (75.2)	39	19	12	6
B455	Exercise tolerance functions*	97 (96.0)	50	27	13	7
b525	Defecation	89 (88.1)	49	21	14	5
b620	Urination functions	94 (93.0)	50	24	13	7
b640	Sexual functions	57 (56.4)	32	15	7	3
b730	Muscle power	96 (95.0)	50	27	13	6
b735	Muscle tone	94 (93.0)	50	26	13	5
b740	Muscle endurance function*	93 (92.0)	49	25	12	7
b760	Control of voluntary movement functions*	66 (65.3)	37	18	8	3
b770	Gait pattern functions*	99 (98.0)	51	27	13	8

*Categories added to the ICF (checklist version 2.1a) (17) after linkage of participant responses. RR: relapsing remitting multiple sclerosis (MS); SP: secondary progressive MS; PP: primary progressive MS; rr-SP: relapsing remitting secondary progressive MS.

Table III. ICF – Frequency of limitation in the linked categories for the component body structure reported by at least one-third (33%) of the participants with multiple sclerosis (n=101)

ICF Code	ICF Code description	Total number of participants linked responses n (%)	Number of participant and stage of disease			
			RR	SP	PP	rr-SP
s110	Brain	100 (99.0)	50	28	14	8
s610	Urinary system	93 (92.0)	49	25	12	7
s730	Upper extremity (arm, hand)	44 (43.5)	25	10	7	2
s750	Lower extremity (leg, foot)	97 (96.0)	49	27	14	7
s760	Trunk	85 (84.1)	44	23	12	6

RR: relapsing remitting multiple sclerosis (MS); SP: secondary progressive MS; PP: primary progressive MS; rr-SP: relapsing remitting secondary progressive MS.

Thirty-eight categories in the “environment” component included: systems and policies (e5) 11 categories, 8 categories each in support and relationships (e3), and for attitudes (e4) and 6 categories for products and technology (e1). Products for personal consumption (medicines) (e1) and climate (e2) were considered relevant.

Tables VI and VII show the ICF categories for components “activities and participation” and “environmental factors”, and the frequency of MS participants-reporting impact (qualifier 1–6) for health areas corresponding with categories for 10 chapters. The most impact reported for corresponding ICF categories in the activities and participation components include:

Table IV. ICF – Frequency of limitation in the linked categories for the component activities and participation reported by at least one-third (33%) of the participants with multiple sclerosis (n=101)

ICF Code	ICF Category description	Total number of participants linked responses. n (%)	Number of participant and stage of disease			
			RR	SP	PP	rr-SP
d160	Focussing attention*	70 (69.3)	39	16	9	6
d175	Solving problems	34 (33.6)	22	8	2	2
d177	Making decisions*	59 (58.4)	35	16	5	3
d220	Undertaking multiple tasks	88 (87.1)	47	24	12	5
d230	Carrying out daily routine*	80 (79.2)	48	17	10	5
d240	Handling stress and other psychological demands*	101 (100)	51	28	14	8
d430	Lifting and carrying objects	53 (52.4)	30	12	8	3
d440	Fine hand use (picking up, grasping)	51 (50.5)	26	13	9	3
d445	Hand and arm use*	37 (36.6)	21	9	4	3
d450	Walking	101 (100)	51	28	14	8
d455	Moving around*	99 (98.0)	51	27	14	7
d465	Moving around and using equipment (wheelchair, skates, etc)	98 (97.0)	50	27	14	7
d470	Using transportation (car, bus, train, plane, etc)	100 (99.0)	51	27	14	8
d475	Driving (riding bicycle and motorbike, driving car, etc)	99 (98.0)	51	27	14	7
d510	Washing oneself (bathing, drying, washing hands, etc)	41 (40.5)	26	9	4	2
d520	Caring for body parts (brushing teeth, shaving, grooming, etc)	40 (39.6)	24	8	5	3
d570	Looking after one’s health	88 (87.1)	47	23	14	4
d620	Acquisition of goods and services (shopping, etc)	92 (91.0)	50	24	12	6
d630	Preparation of meals (cooking, etc)	89 (88.1)	48	24	12	5
d640	Doing housework (cleaning, washing, laundry, ironing)	94 (93.0)	51	23	14	6
d650	Caring for household objects*	84 (83.1)	46	22	12	4
d660	Assisting others	87 (86.1)	48	22	13	4
d750	Informal social relationships	35 (34.6)	19	12	2	2
d760	Family relationships	73 (72.2)	42	16	11	4
d770	Intimate relationships	61 (60.4)	35	15	7	4
d845	Acquiring keeping and terminating a job*	73 (72.2)	39	19	11	4
d850	Remunerative employment	90 (89.1)	45	24	13	8
d870	Economic self-sufficiency	84 (83.1)	44	22	13	5
d910	Community Life	79 (78.2)	40	21	13	5
d920	Recreation and leisure	97 (96.0)	50	26	14	7

*Categories added to the ICF (checklist version 2.1a) (17) after linkage of participant responses. RR: relapsing remitting multiple sclerosis (MS); SP: secondary progressive MS; PP: primary progressive MS; rr-SP: relapsing remitting secondary progressive MS.

Table V. ICF- Frequency of limitation in the linked categories for the component Environmental factors reported by at least one third (33%) of the participants with multiple sclerosis (n=101)

ICF Code	ICF Code description	Total number of participants linked responses. n (%)	Number of participant and stage of disease			
			RR	SP	PP	rr-SP
e110	For personal consumption (food, medicines)	101 (100)	51	28	14	8
e120	For personal indoor and outdoor mobility and transportation	91 (90.1)	47	25	12	7
e150	Design, construction and building products and technology of buildings for public use	70 (69.3)	39	18	9	4
e210	Physical geography*	39 (38.6)	21	11	5	2
e225	Climate	99 (98.0)	50	28	14	7
e310	Immediate family	45 (44.5)	27	9	7	2
e315	Extended family*	42 (41.5)	26	9	3	4
e540	Transportation services, systems and policies	68 (67.3)	38	17	8	5
e580	Health services, systems and policies	79 (78.2)	45	18	11	5

*Categories added to the ICF (checklist version 2.1a) (17) after linkage of participant responses. RR: relapsing remitting multiple sclerosis (MS); SP: secondary progressive MS; PP: primary progressive MS; rr-SP: relapsing remitting secondary progressive MS.

mobility, work, everyday home activities, and community and social activities. Extreme limitation was reported by 77 (77%) participants in ambulating distances > 1 kilometre, 67 (66%) involving sport, 56 (55%) in maintaining employment and 45 (45%) in accessing public transportation. In environmental factors, extreme impact (barrier) was reported by 33 (32%) participants for using products for mobility, 18 (17%) for attitudes of extended family members, 20 (20%) in accessing health resources and 19 (18%) with accessing social security services, and assistance programmes.

DISCUSSION

This study used “linkage rules” to link problems reported by persons with MS living in the community with the individual categories and components of ICF (body function, body structure, activities and participation and environmental factors). This linkage can identify potentially important areas in MS care, and improve our understanding of the participants’ perspective of the impact of MS in relevant areas of health described in the corresponding ICF categories. This can facilitate communication, assessment and management of these persons across settings and interventions (20).

The linkage of problems with the ICF component “body function” identified 10 categories in the mental and orientation function-energy and drive, emotional function, attention and memory. These have been previously reported in MS population (21, 22). The categories from neuromuscular and movement functions (gait, muscle tone, power and endurance) are similar to other reports (23, 24). The issues with continence, fatigue, sexuality and pain are consistent with other series (21, 25–27). Digestive (defecation) function reported by 89 participants was higher than the 70% reported for persons with MS in a recent review (28).

The categories linked with body structures refer to the long-term effects of impairments on movement-related body structures, similar to those reported for neurological patients in post-acute rehabilitation facilities (29).

MS affects all aspects of life and therefore “activities and participation” had a large number of categories represented. These include: mobility, learning and applying knowledge, domestic life, inter-personal, family and intimate relations. These areas are similar to those reported in patients with chronic conditions (stroke, diabetes, arthritis) and mental health conditions (depression) (10). Furthermore, major life areas (economic self-sufficiency, remunerative employment) were in keeping with other studies (30). Climate was an important category identified by the participants with MS. Other environmental categories linked, such as products for personal consumption (medicines), products of technology for use in daily living and for indoor/outdoor mobility, transportation and access to health services, were also reported for patients with chronic conditions (10). The limited access to healthcare services and systems was similar to that reported for patients in the acute hospital (11).

The participant report of impact of MS in the health areas described in the corresponding ICF categories for the 2 components: activities and participation and environmental factors, were as expected. The study population included active “working age” persons in the community, mostly living with family, and driving. The categories in “activities and participation” such as mobility (especially for longer distances), public transport, interpersonal relationships, home and community activities were relevant and similar to the non-MS population. In the environment list the participants reported impact of MS in health areas for corresponding ICF categories for climate, products for personal use and mobility, work, attitudes of friends and access to social security and health services, similar to those reported by neurological patients in acute hospital (11).

Environmental factors can place important restrictions on the degree to which people with MS can participate in the community. Their impact can be greater than the underlying organ system impairments in determining limitation in activity and restriction in participation. The understanding of the environmental factors from the MS participants’ perspective can help assess the barriers and facilitators as perceived by the indivi-

Table VI. Frequency of participants reporting the impact of multiple sclerosis on health areas for corresponding ICF categories for "activities and participation"

Categories	ICF Code	No impact	Minimal impact	Mild impact	Moderate impact	Severe impact	Extreme impact
		0%	1–4%	5–24%	25–49%	50–95%	96–100%
		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
<i>Mobility</i>							
Changing basic body position,	d410	7 (6.9)	11 (10.9)	18 (17.8)	15 (14.9)	29 (28.7)	21 (20.8)
Transferring oneself, transferring when sitting	d420 (d4200)	27 (26.7)	23 (22.8)	18 (17.8)	14 (13.9)	10 (9.9)	9 (8.9)
Lifting and carrying objects	d430 (d4300, 4301)	9 (8.9)	10 (9.9)	14 (13.9)	21 (20.8)	25 (24.8)	22 (21.8)
Moving around in different locations (moving within the home)	d460 (d4600)	19 (18.8)	20 (19.8)	13 (12.9)	19 (18.8)	16 (15.8)	14 (13.9)
Move outside home within the community	d460 (d4602)	8 (7.9)	8 (7.9)	8 (7.9)	12 (11.9)	27 (26.7)	38 (37.6)
Walking	d450 (d4500)	9 (8.9)	4 (4.0)	8 (7.9)	11 (10.9)	12 (11.9)	57 (56.4)
Walk short distances							
Walking long distances (> 1 km)	d450 (d4501)	3 (3.0)	3 (3.0)	4 (4.0)	6 (5.9)	8 (7.9)	77 (76.2)
Driving, driving motorized vehicle	d475 (d4751)	16 (16.2)	17 (17.2)	15 (15.2)	6 (6.1)	9 (9.1)	36 (36.4)
Using transportation, using public motorized transportation	d470 (d4702)	16 (16.0)	9 (9.0)	12 (12.0)	8 (8.0)	10 (10.0)	45 (45.0)
<i>Self care</i>							
Eating	d550	45 (44.6)	14 (13.9)	15 (14.9)	9 (8.9)	11 (10.9)	7 (6.9)
Caring for body parts	d520	41 (40.6)	18 (17.8)	16 (15.8)	8 (7.9)	9 (8.9)	9 (8.9)
Washing oneself	d510	43 (43.0)	9 (9.0)	15 (15.0)	11 (11.0)	12 (12.0)	10 (10.0)
Dressing, upper body	d540 (d5400, 5401)	31 (31.0)	20 (20.0)	19 (19.0)	13 (13.0)	12 (12.0)	5 (5.0)
Dressing lower body	d540 (d5400, 5401)	25 (25.0)	17 (17.0)	16 (16.0)	11 (11.0)	17 (17.0)	14 (14.0)
Toileting	d530	50 (49.5)	14 (13.9)	10 (9.9)	7 (6.9)	9 (8.9)	11 (10.9)
<i>Wellbeing and health</i>							
Looking after one's health, ensuring physical comfort	d570 (d5700)	39 (38.6)	19 (18.8)	13 (12.9)	14 (13.9)	6 (5.9)	10 (9.9)
Managing diet and fitness	d570 (d5701)	59 (59.0)	13 (13.0)	8 (8.0)	7 (7.0)	9 (9.0)	4 (4.0)
Managing one's health	d570 (d5702)	10 (9.9)	7 (6.9)	10 (9.9)	17 (16.8)	18 (17.8)	39 (38.6)
<i>Everyday home activities</i>							
Acquisition of goods & services (shopping)	d620 (d6200)	19 (18.8)	6 (5.9)	13 (12.9)	12 (11.9)	15 (14.9)	36 (35.6)
Gathering daily necessities	d620 (d6201)	26 (25.7)	15 (14.9)	11 (10.9)	16 (15.8)	17 (16.8)	16 (15.8)
Preparing meals	d630	28 (27.7)	14 (13.9)	16 (15.8)	10 (9.9)	17 (16.8)	16 (15.8)
<i>Interpersonal relationships</i>							
Intimate relationship (spouse)	d770 (d7701)	9 (9.8)	12 (13.0)	14 (15.2)	14 (15.2)	11 (12.0)	32 (34.8)
Family relationships (parent child)	d760 (d7600)	12 (18.2)	14 (21.2)	12 (18.2)	10 (15.2)	8 (12.1)	10 (15.2)
Informal social relationship with (friends)	d750 (d7500)	21 (20.8)	16 (15.8)	18 (17.8)	16 (15.8)	15 (14.9)	15 (14.9)
Formal relationships (persons with authority)	d740 (d7400)	40 (45.5)	11 (12.5)	5 (5.7)	4 (4.5)	12 (13.6)	16 (18.2)
<i>Work</i>							
Acquiring, keeping terminating job	d845	15 (15.0)	6 (6.0)	10 (10.0)	3 (3.0)	10 (10.0)	56 (56.0)
Remunerative employment	d850	10 (10.0)	8 (8.0)	8 (8.0)	7 (7.0)	12 (12.0)	55 (55.0)
Non remunerative employment	d855	17 (17.2)	13 (13.1)	9 (9.1)	13 (13.1)	13 (13.1)	34 (34.3)
<i>Community and social activity</i>							
Recreation & leisure (hobbies)	d920 (d9204)	14 (13.9)	8 (7.9)	16 (15.8)	6 (5.9)	14 (13.9)	43 (42.6)
Recreation & leisure (sport)	d920 (d9201)	5 (5.0)	6 (5.9)	4 (4.0)	8 (7.9)	11 (10.9)	67 (66.3)
Recreation & leisure (socializing)	d920 (d9205)	12 (11.9)	7 (6.9)	16 (15.8)	15 (14.9)	20 (19.8)	31 (30.7)
Religion & spirituality (organized religion)	d930 (d9300)	22 (50.0)	7 (15.9)	2 (4.5)	6 (13.6)	2 (4.5)	5 (11.4)
Religion & spirituality (spirituality)	d930 (d9301)	23 (48.9)	9 (19.1)	1 (2.1)	6 (12.8)	2 (4.3)	6 (12.8)

ICF: International Classification of Functioning, Disability and Health.

dual. Adaptation and modification of the environment could then eliminate these barriers and improve participation (9).

Our study has some potential limitations. This is a cross-sectional survey and does not provide longitudinal information. The participants have strict inclusion criteria and are listed in a database of people with MS held at the RMH and who agreed to participate in research projects. The collection of self-report data from patients with cognitive problems, especially those with EDSS scores between 6.5 and 7.5 is challenging. However,

we considered it important to include these persons, who may have very different problems and symptom experience than those less severely affected. In an attempt to reduce recall bias, all questions were limited in the main to the current situation. Medical records were used only to confirm participant report and no additional information was obtained. Wherever possible carers were invited to validate reports, however they were not always available. This method of information gathering has potential information bias. We were not able to identify and

Table VII. Frequency of participants reporting the impact of multiple sclerosis on health areas for corresponding ICF categories for "environmental factors"

	ICF Code	No impact 0%	Minimal impact 1–4%	Mild impact 5–24%	Moderate impact 25–49%	Severe impact 50–95%	Extreme impact 96–100%
		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
<i>Social security & health</i>							
Social security systems and policies	e570	41 (40.6)	9 (8.9)	13 (12.9)	9 (8.9)	10 (9.9)	19 (18.8)
Health services, systems & policies	e580	36 (36.0)	5 (5.0)	9 (9.0)	15 (15.0)	15 (15.0)	20 (20.0)
<i>Attitudes</i>							
Attitudes of extended family members (and friends)	e415, (e420)	28 (27.7)	17 (16.8)	9 (8.9)	15 (14.9)	14 (13.9)	18 (17.8)
Attitudes of healthcare professionals	e450	33 (32.7)	20 (19.8)	15 (14.9)	12 (11.9)	9 (8.9)	12 (11.9)
Attitudes of persons in positions of authority	e430	44 (43.6)	21 (20.8)	17 (16.8)	11 (10.9)	6 (5.9)	2 (2.0)
Societal attitudes	e460	56 (55.4)	14 (13.9)	8 (7.9)	7 (6.9)	9 (8.9)	7 (6.9)
<i>Products and technology</i>							
Personal use daily living	e115	31 (30.7)	15 (14.9)	12 (11.9)	15 (14.9)	9 (8.9)	19 (18.8)
Products and technology for Personal indoor /outdoor mobility	e120, (e1200)	46 (45.5)	13 (12.9)	10 (9.9)	11 (10.9)	10 (9.9)	11 (10.9)
Products and technology for personal transportation	e120, (e1201)	22 (21.8)	8 (7.9)	9 (8.9)	18 (17.8)	11 (10.9)	33 (32.7)
Products for technology for employment	e135, (e1350)	50 (51.0)	13 (13.3)	8 (8.2)	8 (8.2)	7 (7.1)	12 (12.2)
		34 (34.7)	17 (17.3)	9 (9.2)	9 (9.2)	12 (12.2)	17 (17.3)

ICF: International Classification of Functioning, Disability and Health.

link problems with ICF categories not listed by the participants. We did not use the WHO qualifiers scale (0–4) as mentioned nor report concurrent co-morbidities, which may contribute to problems in function. The participant report is subject to interviewers' interpretation; however, ICF categories linked were consistent with medical information available for participants. This consistency can therefore be interpreted as cross-validation of the results. The generalizability and validity of these findings need to be established in future studies.

The aim of this study was to describe the commonly reported problems in MS using the ICF to lay an empirical foundation from the Australian perspective to develop an ICF Core set for MS. This would potentially indicate areas of functional impairment, assessment and management of these persons and facilitate communication in MS care. It can also provide a broader comprehensive framework across patients, settings and interventions that contribute to research in rehabilitation practice (20). Environmental factors identified in this study need further evaluation. The results of this study represent a first step in the use and implementation of the ICF in patients with MS. Based on the experience accumulated from the ICF Core sets developed so far, an important next step would be the development of the ICF Core set for MS from a broader international perspective.

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