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Self-reported Reasons for Changes in Performance of Everyday Activities During a 2-Year

Multidisciplinary Multiple Sclerosis Rehabilitation

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Running head: Daily Activities and Multidisciplinary Rehabilitation

Practice Points

- The 2-year, multidisciplinary, group-based, outpatient rehabilitation program similarly improved the performance of everyday activities in people with moderate and severe disability.

- Long-lasting, multidisciplinary rehabilitation is needed when the rehabilitation goal is to improve participation.

- Individualized analysis of the factors affecting participation is needed.

Abstract

Background: Few multidisciplinary rehabilitation studies with a heterogeneous design have focused on people with multiple sclerosis (MS). This study compared subjective-reported changes in performance and satisfaction with daily activities among moderately and severely disabled people with MS during a 2-year, multidisciplinary, group-based, outpatient rehabilitation program comprising education in self-management and compensatory techniques, exercise, and guided peer support.

Methods: Thirty-eight adults with moderate disability (Expanded Disability Status Scale [EDSS] score of 4.0-5.5, 74% women, mean age of 48 years) and 41 persons with severe disability (EDSS 6.0-8.5, 63% women, mean age of 48 years) were assessed at baseline and after 12 and 21 months of outpatient rehabilitation using the Canadian Occupational Performance Measure. Group $\times$ time interactions were analyzed using mixed analysis of variance. Participants' explanations of reasons for changes in activity performance were collected via semistructured interviews and content analyzed.

Results: Statistically significant improvements in Canadian Occupational Performance Measure performance and satisfaction scores were reported in both groups from baseline to 21 months of rehabilitation. No significant between-group differences in improvement were observed. The self-reported reasons for improvement were mainly linked to environmental factors.

Conclusions: The outpatient rehabilitation program, including four themes—cognition, mood, energy conservation, and body control—improved the self-reported performance of patients with MS with moderate and severe disabilities. Environmental factors warrant consideration during rehabilitation. *Int J MS Care.*

Introduction

Multiple sclerosis (MS) is a chronic, progressive, and unpredictable inflammatory autoimmune disease of the central nervous system.[1] Various combinations of problems at the body function level, such as fatigue, bladder dysfunction, impaired tactile perception, pain, muscle weakness, spasticity, and poor walking balance,[2] hinder functioning in everyday life. The International Classification of Functioning, Disability, and Health (ICF) strongly recommends that various environmental and personal factors[3] be considered when focusing, planning, and conducting holistic, multidisciplinary MS rehabilitation.[4]

A recent review of systematic reviews[5] found moderate evidence supporting multidisciplinary rehabilitation for longer-term gains at the ICF levels of activity and participation. However, the review called for multidisciplinary rehabilitation programs that target long-term functional outcomes, thereby engaging, educating, and empowering patients and their caregivers.

A multiprofessional, 2-year, group-based, outpatient rehabilitation program was developed and implemented to answer the call for holistic, multifaceted, personalized, and goal-oriented rehabilitation for people with MS.[6] Our interest in this study was to investigate whether people with severe and moderate disability would attain the primary goal of the rehabilitation, that is, improvement in performance and satisfaction with daily activities as measured using the Canadian Occupational Performance Measure (COPM). Disease severity was measured using the Expanded Disability Status Scale (EDSS).[7] We hypothesized that on the participation level, those

with severe disability would improve as much as those with lesser disability. We were also

interested in whether the two groups would offer different reasons for changes.

Methods

The study was approved by the research ethics committee of the Social Insurance

Institution of Finland, and all the participants gave their written informed consent according to

the Declaration of Helsinki. The study was retrospectively registered with the International

Standard Randomised Controlled Trials Number registry (identifier: 72556817).

The study sample comprised people with MS participating in a 2-year, multidisciplinary,

group-based, outpatient rehabilitation project conducted by the Finnish Neuro Society, the

Finnish Social Insurance Institution, and the GeroCenter Foundation for Aging Research and

Development. Rehabilitation professionals from the Finnish Neuro Society, together with local

health care professionals, recruited participants from three areas of Finland (ie, Helsinki, Kuopio,

and Turku).

Recruitment was implemented from May 2010 to August 2010 using convenience

sampling. Predefined inclusion criteria were age 18 through 62 years, confirmed diagnosis of

MS, and restrictions on functioning in at least two of the following four focal domains:

cognition, mood, fatigue, and body control. Restricted functioning in these domains was assessed

subjectively and by a rehabilitation physician and coded as restrictions versus no restrictions.

Exclusion criteria were a Mini-Mental State Examination score less than 20 of 30 (ie, severe

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cognitive decline), a Beck Depression Inventory II score greater than 40 of 63 (ie, severe

depression), an EDSS score less than 4.0 or greater than 8.5, or any other medical or mental

condition precluding participation.

Sociodemographic data, including sex, age, housing status, receiving a disability pension,

and disease characteristics (including disease duration and subtype), were collected before

rehabilitation. Severity of MS was evaluated by a neurologist using the EDSS. The EDSS score

ranges in increments of 0.5 from 0 (no impairment) to 10 (death).[7]

The primary outcome measure was the client-centered COPM, which is designed to

identify clients' occupational performance problems.[8] The COPM is a semistructured interview

addressing the activities that the client wants, needs, or is expected to perform. First, together

with the therapist, the client explores the different areas of daily life, including self-care,

productivity, and leisure, and lists the activities subjectively experienced as difficult to perform.

The client rates the importance of each of these activities on a 10-point scale. Next, the client

chooses up to five of the most important activities and rates them for performance and

satisfaction on a 10-point scale (1 = not able to do it at all/not satisfied at all; 10 = able to do it

extremely well/extremely satisfied). Finally, for each rated activity, mean scores for performance

and satisfaction are calculated. Persons were assessed at baseline (T0) and after 12 months (T1)

and 21 months (T2) of rehabilitation. At T1 they were asked to rate their performance and

satisfaction with the problems prioritized during the baseline COPM interview blinded to their

T0 assessment scores (blind scores). In addition, at T2, clients were asked to give their reasons

for change with the open question "How would you explain your improving, unchanged, or

deteriorated performance in the activities of everyday living identified by the COPM?" The interviews were tape-recorded. The main reasons given for changes in performance in each activity were summarized from the recorded data and transcribed. All the interviews were implemented using a literal protocol for assessment by four occupational therapists who had no involvement in the rehabilitation program.

Intervention

The goal of the 2-year, multidisciplinary, group-based rehabilitation program was to provide participants with a means to manage the effects of MS that would support their active participation in everyday life. The intervention was designed based on the current literature on MS, MS rehabilitation, and professional experience.[6] The themes of the rehabilitation program addressed the most common participation limitations experienced by patients with MS: cognition,[9] mood,[10] energy conservation,[11] and body control.[12,13] Group sessions included not only the dissemination of information on the themes and on compensation strategies in everyday life but also opportunities for peer support and the sharing of experiences of coping strategies helpful in everyday life. Participants were also instructed in home exercises related to the themes.

Each theme was implemented in two versions: a short version comprising five 3-hour sessions and one whole-day session (one semester) and a long version consisting of ten 3-hour sessions and two whole-day sessions (two semesters). Participants attended sessions on two to

four themes in groups of four to six persons. Participants chose themes based on their needs and

personal goals in relation to the ICF activity and participation levels. Each participant attended

20 half-day sessions and four whole-day sessions in total during the 2-year rehabilitation

program.

Caregivers could participate in one half-day and one whole-day session each semester.

Each participant had a personal supervisor who was responsible for coordinating the participant's

program and cooperating with other institutions and communities when necessary. Two

rehabilitation professionals from different disciplines (physiotherapist, psychologist,

neuropsychologist, occupational therapist, nurse, social worker) guided the theme groups

according to a detailed handbook, which is available in Finnish on request from the authors. In

addition to group meetings, the rehabilitation program included three to five individual home

visits for individual-based assessment of functioning, goal setting, and guidance.

Data Analysis

Quantitative data were analyzed using SPSS Statistics for Windows, version 21.0 (IBM

Corp). To compare changes between the moderately and severely disabled MS groups in their

performance of and satisfaction with everyday living across T0, T1, and T2, scores were

analyzed by mixed analysis of variance with a between-subject factor. First, mixed analysis of

variance was conducted to ascertain possible interaction between the moderately or severely

disabled MS groups (between-subjects factor) and time (within-subjects factor) on their

performance of and satisfaction with everyday activities. If no interaction was observed, follow-up tests were performed to determine possible main effects for either factor (ie, group or time). Post hoc pairwise comparison tests were performed with Bonferroni correction.[14]

Before the analysis, the main assumptions of the data were assessed. Normal distribution of the data was confirmed by a box plot and the Shapiro-Wilk test ($P > .05$). No outliers were observed in either scatterplots or box plots. Moreover, the assumption of sphericity was tested using the Mauchly test of sphericity.

The proportions of participants who reached a clinically relevant change were analyzed using the thresholds proposed by Eyssen et al[15] (>1.4 points for COPM performance and >1.9 points for COPM satisfaction).

Qualitative data were analyzed by theory-driven content analysis.[16] Before starting the analysis process, the researchers (M.E.K. and K.K.) agreed on the steps to be followed in the content analysis. First, one researcher (K.K.) condensed the reasons for change into plain expressions, created a table, and imported it into an Excel spreadsheet (Microsoft Corp). The other researcher (M.E.K.) agreed or disagreed with the expressions used. The first researcher (K.K.) then continued the analysis by coding the plain expressions mutually agreed on into the ICF components and submitting the results to the other researcher (M.E.K.) for confirmation. For example, a client who had selected "carrying objects" as a problem in everyday life gave as a reason for postintervention change that "although my condition is now worse than before and I can't use a walker, I can carry objects better because I now use a wheelchair. I am also satisfied that I can carry objects on my own." This meaning unit was condensed to the plain expression

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"doing daily tasks in a new way." The condensed meaning unit was then coded into the personal

factors component of the ICF. Finally, the researchers discussed points of disagreement and

reached a consensus. A third researcher (A.-L.S.) was available for consultation when a

consensus could not be reached.

Results

Ninety people with MS started the rehabilitation program, and 79 were included in the

analysis: 11 withdrew from the study owing to lack of motivation (n = 4), changed health

condition (n = 2), unsuitability for a group-based intervention (n = 1), refusal to take part in

assessments (n = 2), assessments only partially conducted (n = 1), and in-patient care (n = 1).

The study flowchart is presented in Figure S1 (published in the online version of this article at

ijmsc.org).

The characteristics of the participants with moderate (n = 38) and severe (n = 41)

disability are presented in Table 1. No statistically significant between-group differences were

observed in age, disease duration, sex, or proportion of those living alone or receiving a

disability pension. However, there were more cases of relapsing-remitting MS in the moderately

disabled group and more cases of secondary progressive MS in the severely disabled group. No

within-group or between-group differences, measured using the *t* test, were found in EDSS

scores during the intervention.

No between-group differences were found in COPM performance (P = .26) or COPM satisfaction (P = .80) between the moderate and severe groups during the 21-month intervention. In both groups, COPM performance and satisfaction scores improved significantly (both P < .001). No significant group × time interaction was found in assessments of COPM performance (P = .91) or COPM satisfaction (P = .92) (Figure 1).

Post hoc analysis with a Bonferroni adjustment revealed that COPM performance in the moderately disabled group improved significantly from T0 to T2 (1.0; 95% CI = 0.2-1.8, P = .006). The COPM performance improved significantly in the severely disabled group from T0 to T2 (1.2, 95% CI = 0.4-1.9, P = .001) and from T1 to T2 (0.7, 95% CI = 0.1-1.3, P = .016). The COPM satisfaction in the moderately disabled group also improved significantly from T0 to T2 (1.5, 95% CI = 0.6-2.5, P < .001) and from T0 to T1 (1.1, 95% CI = 0.3-2.0, P = .004) and in the severely disabled group from T0 to T2 (1.6, 95% CI = 0.7-2.6, P < .001) and from T0 to T1 (1.0, 95% CI = 0.2-1.8, P = .007).

No significant differences were found between the moderately and severely disabled groups in the proportion of clinically relevant changes in COPM performance or satisfaction scores. A clinically relevant change (>1.4 points) in COPM performance was reached by 35 participants (44%). The threshold value for clinically relevant change in COPM satisfaction, that is, 1.9 points, was reached by 31 participants (39%).

Participants presented 171 reasons for improved, 103 reasons for stable, and 77 reasons for deteriorated performance in activities of daily life. More than 80% of the reasons for improvement were linked to the ICF environmental and personal factors components. Reasons

for stable or declining performance were most commonly linked to the ICF personal factors

component (Table S1). The most prevalent reasons linked to the personal factors component

were general state of health, a new way of doing daily tasks, and a new way of dealing with

situations and activities. Both improvement and decline in everyday activities were also

attributed to general health condition. Reasons linked to the environmental factors component

included the physical environment, such as devices and environmental modifications, the social

environment, and assistance. Furthermore, using different kinds of formal and informal services

was cited as improving everyday activities. The reasons linked to the body functions component

were related to mental functions such as energy, drive, and pain. Only 5% of reasons were linked

to the activity and participation component, and the most common reasons were caring for

oneself by maintaining physical fitness and getting or not getting a job.

Discussion

The results of this study indicate that performance of and satisfaction with everyday

activities did not differ between moderately and severely disabled people with MS during a 21-

month rehabilitation program. The most important finding was that both groups improved in

COPM performance and COPM satisfaction during the intervention. Two years is a fairly short

time in the context of MS progression. The changes in disease severity (EDSS score)[7] between

the baseline and postintervention measurements suggest that participants' clinical status remained

stable during the intervention. The results thus seem to be reliable and confirm earlier research

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findings that the performance of everyday activities can improve, even in people with progressive disease.[17] However, note that the EDSS is not a very sensitive scale when used with participants, such as ours, whose scores are in the higher range.

The four-theme (body control, mood, energy conservation, and cognition) multidisciplinary rehabilitation program, comprising components such as theme-based sessions with peer support, home visits, and sessions for loved ones, succeeded in meeting the functional needs of people with moderate and severe MS, that vary from individual to individual and also change as the disease progresses and symptoms change.[18,19] This study supports a previous finding that disease severity does not explain the importance of specific activities.[20] In addition, the intervention underlined the importance of addressing the primary goal of rehabilitation,[4] that is, of improving participation in everyday activities, in the later and advanced stages of MS.

Another interesting finding was that satisfaction with important everyday activities improved before the perceived improvement in performance. Satisfaction improved in both groups from the beginning to the middle of the rehabilitation program. This improvement seemed to continue, if not statistically significantly, to the end of the program. One explanation for this apparent trend is that the first step toward change is to identify a challenging activity. This could motivate working on the challenging activity and increasing the feeling of mastery and satisfaction that comes with it. This is in line with the theory that as a person identifies goals that are relevant to him or her in everyday life, motivation also improves and behavioral changes also become possible.[21] However, 44% of the participants in this study clinically improved their COPM performance scores (threshold >1.4 points[20]) and 39% clinically improved their COPM

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satisfaction scores (threshold >1.9 points[15]). A previous study on the self-management of fatigue in people with MS similarly showed that clinically relevant changes were achieved more frequently in performance than in satisfaction.[17]

A previous review showed that multidisciplinary rehabilitation improves participation outcomes up to 12 months after rehabilitation start.[22] However, the present results indicate that improvement also occurred after the first year. Performance of everyday activities in the moderate disability group improved continuously during both rehabilitation years, whereas in the severe disability group performance improved more during the second year. Hence, it is important to continue rehabilitation for a sufficiently long period. Moreover, consistent with a previous report,[6] and with previous studies showing that challenges in everyday life are multiple,[18,23] the self-reported reasons for changes in everyday activities were diverse. These results suggest that clinicians and people with MS should consider together which factors influence specific everyday activities. In so doing, the ICF classification could be used as a frame of reference, assisting clinicians to select an appropriate intervention, for example, training, learning compensation strategies, or modifying the patient's environment. In the advanced stages of MS especially, rehabilitation should concentrate on environmental factors and alternative ways of coping.[4]

Environmental and personal factors seemed to play an important role in the performance of and satisfaction with everyday activities of persons with MS. In each rehabilitation phase—assessment, goal setting, and selecting the intervention—it is essential to eliminate hindering and promote facilitating factors.[24,25] In clinical practice, it is important to recognize that even a small

action can induce notable changes in everyday life if conducted in the right place and at the right time. For example, in this, as in previous studies,[26,27] identification of the need for assistive devices or environmental modifications resulted in major changes in everyday life.

The fact that personal factors are not defined in the ICF classification can lead to their being overlooked when planning interventions. The present findings encourage a stronger focus on personal factors. Participants accented a number of personal factors that enable them to perform daily activities, such as learning new ways of doing activities or of awaiting challenging situations. Although closely connected to the ICF activity and participation component, these factors were classified under personal factors because they represent changes in behavior patterns and styles.[28] This study corroborates an earlier finding[29] on the centrality of motivation, coping, and action planning in a health promotion intervention. Moreover, self-awareness of functional status has been observed to influence daily activities and participation.[30]

The diversity of reasons for change in the performance of everyday activities found in this study highlights the value of other theories in addition to treatment theories. The enablement theory might give an insight into, and help model, complex functions that are multiply determined.[31] Furthermore, different behavior change theories, such as the theory of intentional action control,[32] can help us understand how persons translate their goals into actions and how their actions can be supported to reach goals in complex situations affected by multiple factors. Moreover, integrating the three core elements of a client-centered approach—effective communication, partnership, and health promotion[33]—into the intervention process would ensure that a person's unique life situation and needs are its starting point.

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The present study has several strengths. First, the design, which incorporated quantitative and qualitative data to ascertain the reasons for improvement, enables a multifaceted view of the outcomes of MS rehabilitation. Second, the study adopted a client-centered approach prioritizing individuals' subjective experience of changes in their performance of and satisfaction with self-selected everyday activities, and their own views of the reasons for improvement. Third, compared to most of the interventions studied earlier, the current intervention was significantly longer in duration. Fourth, the COPM proved to be valid, reliable, clinically useful,[34] and sensitive enough to measure changes in everyday activities from the perspectives of performance and satisfaction.[35]

Despite the strengths of the study, its generalizability is influenced by the study population and study design. The sample was limited to persons with moderate-to-severe disability. Therefore, the results cannot be generalized to persons with mild disabilities. In addition, there was no actual observation of activity performance. The pre-post design without controls enabled comparison of improvement between moderately and severely disabled groups during the 2-year rehabilitation. However, to fully evaluate the effectiveness of multidisciplinary long-term MS rehabilitation programs calls for more studies with randomized controlled trial designs.

The COPM as a self-evaluation method also has its limitations. Results could have been influenced by the phenomenon known as "response shift." It is described as a cognitive appraisal process in which individuals' self-assessment is influenced by different internal standards or values, or how individuals understand the concept being assessed.[36] The response shift can occur

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in three different ways: first, over time or as the disease changes, internal standards of participation may change (recalibration); second, the values may change (reprioritization); and third, over time, the individual may define the concept differently than before (reconceptualization).[37] The life situations of the participants changed during the 2-year rehabilitation program. In addition, the activities that some participants considered important at the beginning of the rehabilitation program no longer seemed important at the end of the rehabilitation program (reprioritization). Therefore, it is worth noting that in the 12- or 21-month assessments, about 10% of the activities were such that participants did not assess improvement in them. For example, walking the dog was no longer relevant after its death, or, owing to worsening of the disease, a previously important activity, such as sauna, no longer offered a pleasurable experience (recalibration).

In conclusion, the 2-year, multidisciplinary, group-based, outpatient rehabilitation program improved performance of and satisfaction with everyday activities among people with moderate and severe MS. However, the use of a pre-post study design without controls limits the generalizability of the results. Although self-reported reasons for change during the rehabilitation were diverse, personal and environmental factors especially seemed to have an important role. It is, therefore, recommended that participants' personal experiences of the factors affecting their everyday activities are regularly captured during the rehabilitation process.

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Figure 1. **Comparisons of Canadian Occupational Performance Measure (COPM) performance (A) and satisfaction (B) in moderately (n = 38) and severely (n = 41) disabled multiple sclerosis groups during 21-month rehabilitation program**
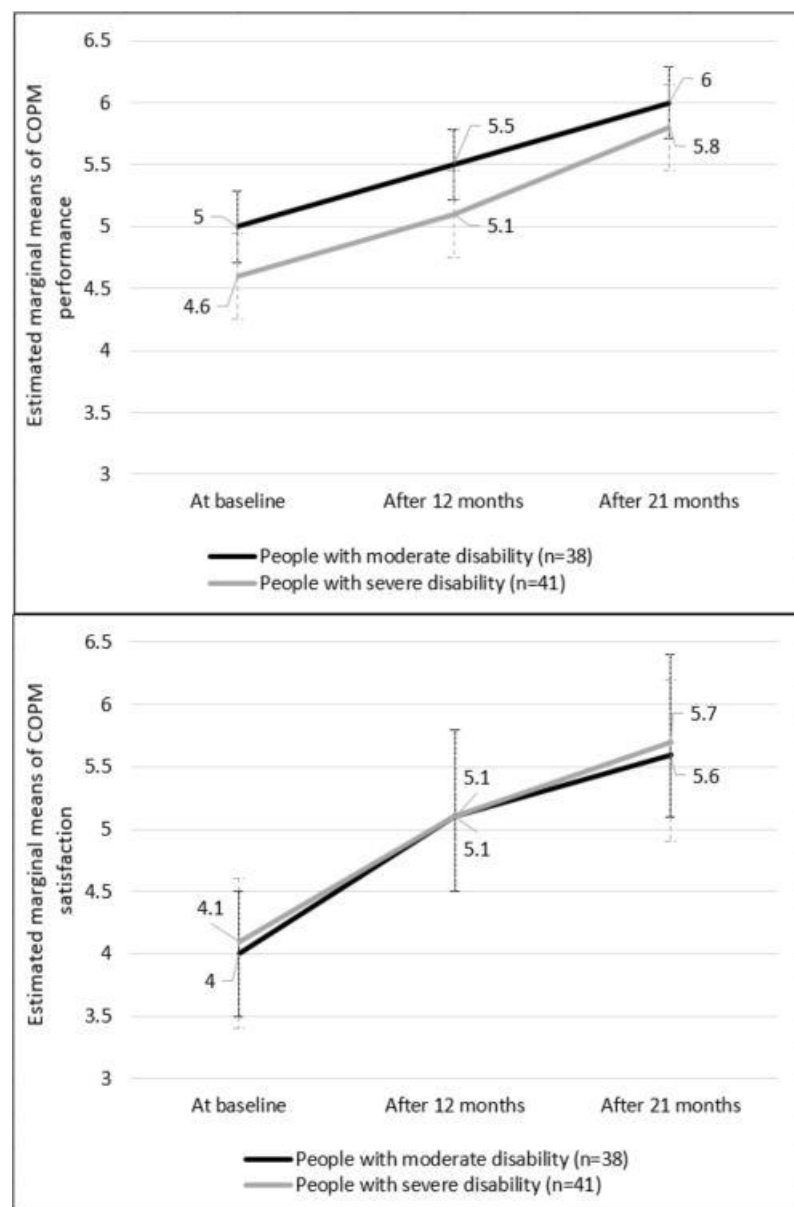
Table 1. **Characteristics of the 79 study participants**

Characteristic	Moderate disability (EDSS score 4.0-5.5) (n = 38)	Severe disability (EDSS score 6.0-8.5) (n = 41)	*P* value (between-group differences)
Age, y	48 ± 9 (28-61)	48 ± 9 (29-61)	.919[a]
Duration of disease, y	10 ± 7 (0-25)	13 ± 7 (1-28)	.095[a]
Sex			.327[b]
Male	10 (26)	15 (37)	
Female	28 (74)	26 (63)	
Living alone	8 (21)	14 (34)	.427[b]
Disability pension	28 (74)	29 (71)	.770[b]
Disease subtype			.050[b]
Relapsing-remitting	21 (55)	13 (32)	
Primary progressive	10 (26)	11 (27)	
Secondary progressive	7 (19)	17 (41)	
Disease severity (EDSS score)			
At baseline	4.5 ± 0.6	6.6 ± 0.7	<.000[a]
At 21 mo	4.6 ± 0.9	6.7 ± 0.9	<.000[a]

Note: Data are given as mean ± SD (range), number (percentage), or mean ± SD.

Abbreviation: EDSS, Expanded Disability Status Scale.

[a]*t* test.

[b]χ^2 test.

Table S1. **Self-reported reasons for changes in the performance of everyday activities linked to the ICF components and chapters**

ICF component and chapter	Category of reasons	Improving (n)		Stable (n)		Declining (n)	
		moderate disability	severe disability	moderate disability	severe disability	moderate disability	severe disability
Body functions, total (n)		**8**	**11**	**4**	**4**	**3**	**3**
1. Mental functions	b130 Energy and drive functions (to move towards goals)	3	5	2		2	3
	b126 Temperament and personality functions (psychic and emotional stability)	2	4			1	
	b152 Emotional function (regulation of fear or tension, coping stress) during activity	2	2	1	3		
2. Sensory functions and pain	b280 Sensation of pain	1		1	1		
Activities and participation, total (n)		**7**	**2**	**7**	**2**	**0**	**2**
1. Learning and applying knowledge	d179 Applying knowledge (learning to use computers and mobile phone)	1					
4. Mobility	d475 Driving (a car)						1
	d489 Moving around using transportations (trips to the place where activity is done)			1	1		
5. Self-care	d570 Looking after one's health (caring for oneself by maintaining physical fitness)	6		3			
7. Interpersonal interactions and relationships	d750 Informal social relationships (relationships with friends)		1	1			
8. Major life areas	d845 Acquiring, keeping, and terminating a job (acquiring a job)		1				
	d845 Acquiring, keeping, and terminating a job (not acquiring a job)			2	1		1
Environmental factors, total (n)		**42**	**39**	**10**	**15**	**6**	**1**

1. Products and technology	e115 Products and technology for personal use in daily living e120 Products and technology for personal indoor and outdoor mobility and transportation (getting assistive products and technology for personal use in daily living and mobility)	14	8				
	e115 Products and technology for personal use in daily living e120 Products and technology for personal indoor and outdoor mobility and transportation (not getting appropriate assistive products and technology for personal use in daily living and mobility)			3	1	1	
	e110 Products or substances for personal consumption (new medication)	5					
	e155 Design, construction and building products, and technology of buildings for private use (environmental modifications done)	6	4				
	e155 Design, construction and building products and technology of buildings for private use (environmental modifications not done)			6	13	2	1
2. Natural environment and human-made	e298 Natural environment and human-made changes to environment, other	2	2				

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changes to environment	specified (finding an appropriate natural environment for activity)						
3. Support and relationships	e340 Personal care providers and personal assistants (personal assistance, new service)	6	13				
	e340 Personal care providers and personal assistants (personal assistance, same as before/not getting service)				1	2	
	e310 Immediate family e320 Friends (assistance from family and friends)	1	2	1		1	
	e310 Immediate family (changes in social relationships, eg, child has grown up)	3	4				
5. Services, systems, and policies	e510 Services, systems, and policies for the production of consumer goods (carrying out plans to use different kinds of services)	1	3				
	e510 Services, systems, and policies for the production of consumer goods (using self-paid services, eg, house-cleaning)	1	1				
	e540 Transportation services, systems, and policies (travel services for leisure trips)	3	2				
Personal factors, total (n)		**38**	**24**	**26**	**35**	**37**	**25**
Not defined	Doing daily activities in a new way	17	14				
	Doing daily activities in the same way			6	11		
	General health condition	11	5	16	21	37	25
	A way to deal with situation and activity (eg, anticipation)	4	3	2	1		

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	Compensative way of doing	2					
	Prioritising activities	3	2	2	2		
	Life situation getting easier	1					

Abbreviation: ICF, International Classification of Functioning, Disability, and Health.

Figure S1. **Study flowchart**