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Participation in social/lifestyle activities in people with multiple sclerosis: Changes across 10 years and predictors of sustained participation

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Abstract

Background: Identification of people with multiple sclerosis (PwMS) with increased risk of restricted participation in social and lifestyle activities (e.g. social outings and pursuing a hobby) could guide the development of interventions supporting sustained participation.

Objective: To explore changes in participation in complex and social everyday activities over 10 years in PwMS in relation to multiple sclerosis (MS) severity and to identify predictors of sustained participation.

Methods: This study was based on a 10-year follow-up of 264 PwMS living in Stockholm County, Sweden. Ten-year changes in participation in social/lifestyle activities were assessed and compared between PwMS with different MS severity with the Frenchay Activities Index using age- and sex-related normative values. Multiple logistic regression analyses were used to predict sustained participation at 10 years using personal factors, disease severity and functioning as independent variables.

Results: While a majority of people with mild MS demonstrated sustained participation (67%), a minority of PwMS moderately (26%) and severely affected by MS (5%) demonstrated sustained participation. Significant predictors of sustained participation after 10 years were walking speed ⩾1.2 m/s and ⩾32 correct responses on the Symbol Digit Modalities Test.

Conclusion: Our findings accentuate the importance for health services to support mobility and cognition to obtain sustained participation.

Keywords: Disease progression, epidemiology, longitudinal study, participation, mobility

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Introduction

Participation can be understood as involvement in a life situation, for example, be part of activities in societal contexts, according to the international classification of functioning, disability and health.[1] The World Health Organization has identified sustained participation as an important global goal of the health systems.[2] Interventions that help individuals to participate in society on an equal basis with others, for example, interacting and participating in community events and activities, should therefore be developed and implemented.[3] As a first step, it is essential to understand the long-term course in participation for individuals with chronic diseases.

People with multiple sclerosis (PwMS) make up a certain risk group for restricted participation as they often experience progressive disability across different domains of functioning (e.g. walking, manual dexterity and cognition) over decades.[4–7] In fact, reduced ability to engage in activities that comprise a certain degree of complexity regarding initiative and planning is common even in PwMS mildly and moderately affected by multiple sclerosis (MS)[8] – varying from 21% in the mild group to 73% in the moderate group – which in turn has a negative impact on quality of life.[8,9] While most previous longitudinal studies have shown restricted participation in complex social/lifestyle activities (e.g. social outings or

pursuing a hobby) in PwMS,[10,11] others have demonstrated sustained[6] or improved participation across time.[12] Notably, most aforementioned studies have explored the overall change in participation of large heterogonous MS cohorts with a follow-up period of 6 years or shorter. However, as recent studies have demonstrated different courses of disability between PwMS with different disease severity,[5,13] it is likely that the trajectory of participation also varies between severity groups. Furthermore, although cross-sectional studies have shown that disability in walking, dexterity and cognition are associated with restricted participation in PwMS,[14–16] little is known about predictors of sustained participation in the long-term perspective. Early identification of individuals with an increased risk of restricted participation could guide the development of interventions fostering sustained participation in PwMS.

The overarching goal of this study was therefore to explore changes in participation in complex and social everyday activities over a 10-year period in PwMS in relation to disease severity and to identify predictors of sustained participation. For the identification of predictors, we focused on personal factors (e.g. age, living situation, work and education) and different domains of functioning, such as walking, manual dexterity and cognition.

Material and methods

Study design and participants

This study was a secondary analysis of pooled data from 10-year follow-ups of two similar MS cohorts in Stockholm, Sweden. The first study was a population-based study in which 158 of 188 eligible PwMS who were residents in Stockholm County participated at baseline.[6,17] Baseline assessments were performed between September 1999 and September 2002, the 10-year follow-up was conducted between 2009 and 2012. The second study, an outpatient-based cohort recruited from the MS Centre at Karolinska University Hospital, Stockholm, included a total of 219 of 255 eligible PwMS at baseline. Baseline assessments were performed between February 2002 and June 2002, the 10-year follow-up was conducted during 2012.[5,8] All participants were living in the community, at baseline diagnosed with MS according to Poser criteria, and had no other severe neurological or psychiatric diseases. This study was approved by the Regional Board of Ethics in Stockholm (registration numbers 2018/876-32/3 and 2018/963-32). All participants received information about the study and written informed consent was obtained before enrolment.

Data collection

Data collection took place either at the Karolinska University Hospital or in the participant's home. Table 1 summarises the variables studied, instruments used and the criteria for categorisation of independent and dependent variables. The cut-off points used for categorisation of the independent and dependent variables were based on previous literature in MS (see references in Table 1).

Personal factors and disease severity

Data on age, sex, living situation, work status, education and use of mobility devices were collected using standardised face-to-face interviews. Disease severity was determined using the Expanded Disability Status Scale (EDSS), classified as mild MS (EDSS: 0–3.5), moderate MS (EDSS: 4–6.5) and severe MS (EDSS: 7–9.5). Information about immunomodulatory treatment was also collected and the course of MS was determined as relapsing-remitting or progressive MS.

Functioning

Ambulation status was tested with the Timed 2×5 m walk test[21] in the population-based cohort and with the Timed 25-Foot Walk[22] in the outpatient-based cohort. For both tests, gait speed was calculated and participants were classified to the following ambulation categories: limited ambulator (0−1.2 m/s) and community ambulator ($\geqslant$1.2 m/s).[18] Manual dexterity of the dominant hand was assessed with the Nine-Hole Peg Test (NHPT).[23] Aspects of cognitive function – from now on referred to as 'cognition' – was assessed with the Symbol Digit Modalities Test (SDMT)[24] which measures processing speed and is recommended as a screening measurement for PwMS.[25] The SDMT was primarily administered in written format, but for PwMS with severe upper extremity motor impairments, the test was administered orally. An average of two trials was calculated to decide maximum speed (m/s) for ambulation and number of pegs/s for manual dexterity. For the number of correct responses for SDMT, a single performance was analysed. For PwMS who were unable to perform the walking, manual dexterity or cognitive assessment, the result was set to 0 (i.e. 0 m/s, 0 pegs/s and 0 correct responses/s). Mood was assessed using the Beck Depression Inventory (BDI).[19]

Participation

Participation in social and lifestyle activities was assessed with the Frenchay Activities Index (FAI).[26] We operationalised the FAI within the participation

Table 1. Variables, instruments and criteria used for categorisation of the independent variables and the dependent variable.

Variables and instruments	Criteria for categorisation
Independent variables	
Age	<41 years/≥41 years
Sex	Female/male
Living situation	Living alone/co-habiting
Work status	Working (full- or part-time)/not working
Education	Basic (i.e. high school, primary or lower secondary level)/higher education (i.e. university or higher)
Immunomodulatory treatment	Treatment/no treatment
MS type	Relapsing MS/progressive MS
Ambulation status: Timed 25-Foot Walk and Timed 2 × 5 m walk test[a]	Limited ambulator (0−1.2 m/s)/community ambulator (≥1.2 m/s)[18]
Manual dexterity: Nine-Hole Peg Test[a]	Impairment (<0.5 pegs/s)/no impairment (≥0.5 pegs/s)[15]
Cognition: Symbol Digit Modalities Test[a]	Impairment (<32 correct responses)/no impairment (≥32 correct responses)[15]
Mood: Beck Depression Inventory	Depressive symptoms (≥13)/no depressive symptoms (<13)[19]
Dependent variable	
Participation in social/lifestyle activities: Frenchay Activities Index	Restrictions (<25th percentile)/no restrictions (≥25th percentile) of age- and sex-related norms.[20]

MS: multiple sclerosis.
[a]Speed calculation/result was set to 0 for people with multiple sclerosis unable to perform the test.

domain since this instrument mainly evaluates engagements in more complex activities, often involving more than one task/action, which require initiative, organisation and planning on the part of the individual (e.g. social outings, pursuing a hobby).[27] The FAI contains 15 items covering three sub-domains with varying complexity: domestic chores (e.g. preparing meals, washing clothes and heavy housework), outdoor (e.g. local shopping, walking outside and driving car/going on bus) and work/leisure activities (e.g. social outings, pursuing a hobby and reading).[26] Based on how often the activities have been performed the last 3 or 6 months, each item is scored between 0 and 3 and summarised as a total score for the three respective sub-domains or as a total score of all items. The FAI was developed for people with stroke,[26] and it has been shown to be reliable and valid in older adults and people with MS.[15,20] Participants who demonstrated an FAI-total score within the 25th percentiles of age and sex norm values[20] at baseline and the 10-year follow-up were classified as having no restrictions in participation in social/lifestyle activities. Thereafter, we classified the change between baseline and the 10-year follow-up according to four categories: (1) unchanged – restricted (i.e. restrictions at baseline and follow-up); (2) declined participation (i.e. restrictions at follow-up but not at baseline); (3) unchanged – not restricted (i.e. no restrictions at baseline and follow-up); and (4) improved participation (i.e. restrictions at baseline but not at follow-up). Finally, participants who belonged to group 3–4 were classified as having sustained levels of participation.

Analysis

Statistical analyses were carried out using IBM SPSS, version 23.0 (SPSS Inc., Chicago, Illinois, USA). Numbers (percentages) were used to present demographics (sex, age, living situation, work status and education level), MS-related variables (disease course, severity, immunomodulatory treatment) and functioning (ambulation status, dexterity, cognition and mood). The chi-square test was used to test for baseline differences between the population-based cohort and the outpatient-based cohort and between those who completed the 10-year follow-up and those who dropped out. For the first aim, due to not normally distributed data, the Wilcoxon signed-rank test was used to analyse within-group changes for FAI variables between baseline and the 10-year follow-up in PwMS with mild, moderate and severe MS. For the second aim, potential predictors for sustained participation were entered one at a time in unadjusted univariate logistic regression models (see Table 1). At this point, the cut-off to include factors in the multivariate analyses was set to an alpha level $p \leq 0.1$. Prior to multivariable analyses, measures of association, that is, chi-square

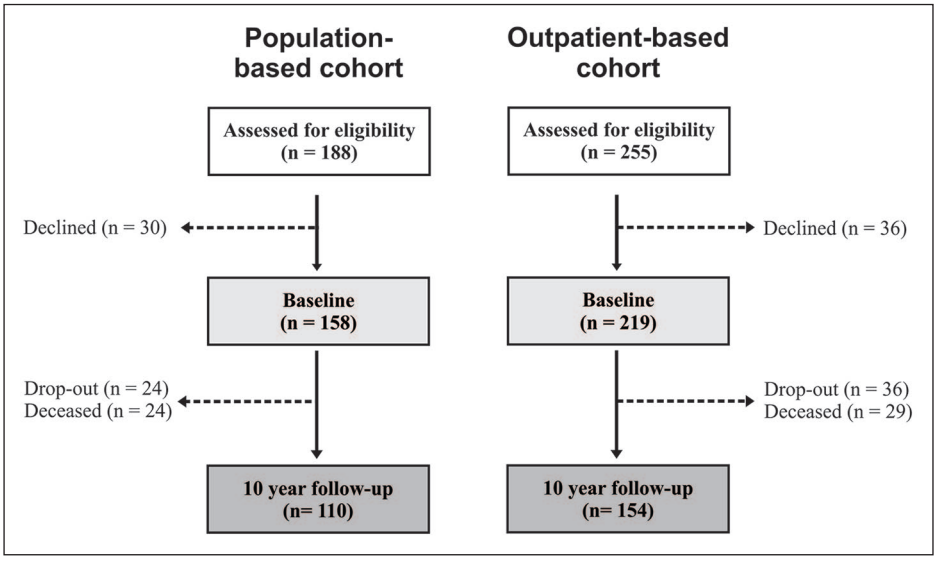

Figure 1. Study flowchart for the population-based and outpatient-based cohort.

tests, were computed to assess for collinearity among potential predictors. Intercorrelations between the independent variables are presented in Supplementary Material 1. Predictors were subsequently entered into a multivariable logistic regression model with an alpha level set at $p \leqslant 0.05$ for the identification of independent predictors. The predicted model was found to have acceptable discrimination if the area under the receiver operating characteristic curve was $\geqslant 0.70$.

Results

Participants' baseline characteristics

Of the 377 PwMS enrolled in the two original studies, 264 participated in the 10-year follow-up – 110 from the population-based and 154 from the outpatient-based cohorts (see Figure 1 for flowchart and Table 2 and Supplementary Material 2 for baseline characteristics). Compared to the outpatient-based cohort, a larger proportion of the population-based cohort was not working at baseline (51% vs 38%, $p = 0.042$), was not receiving immunomodulatory treatment (41% vs 86%, $p < 0.001$) and had progressive MS (55% vs 36%, $p < 0.001$). The population-based cohort also demonstrated greater disease severity, larger limitations in ambulation status and in manual dexterity compared to the outpatient-based cohort ($p \leqslant 0.042$, see Table 2).

Participants lost to follow-up

Of those not participating in the 10-year follow-up, 61 were deceased and 51 declined to participate. The proportions of participants who dropped out and reasons for doing so were similar between the two MS cohorts. Compared to those completing the study, a larger proportion of those not participating lived alone (41% vs 26%, $p = 0.004$), were not working (74% vs 42%, $p < 0.001$), had progressive MS (63% vs 44%, $p < 0.001$) and severe MS (39% vs 14%, $p < 0.001$). As illustrated in Table 2, those lost to follow-up also demonstrated a more severe disability profile for cognition and larger limitations in manual dexterity ($p \leqslant 0.003$).

Changes in participation in complex and social everyday activities

Of the 264 PwMS included in this study, 119 (45%) PwMS demonstrated sustained participation between baseline and 10 years (see Table 3). While a majority of people with mild MS demonstrated sustained participation ($n = 95$, 67%), a minority of PwMS moderately ($n = 22$, 26%) and severely affected by MS ($n = 2$, 5%) demonstrated sustained participation. Significant decline in all domains of participation occurred for PwMS with mild, moderate and severe MS between baseline and the 10-year follow-up (see Table 4).

Predictors of sustained participation

Univariate logistic regression analyses (Table 5) revealed that PwMS who were <41 years of age (odds ratio (OR) = 1.99, $p = 0.012$), with relapsing MS (OR = 4.87, $p < 0.001$) and higher education level (OR = 1.97, $p = 0.008$) were more likely to sustain their participation between baseline and the 10-year follow-up. Furthermore, PwMS who were community ambulators (walking speed: $\geqslant 1.2$ m/s,

Table 2. Baseline data for the population-based and outpatient-based MS cohorts and those dropping out from the study.

Variables	Population-based ($n=110$)	Outpatient-based ($n=154$)	All ($n=264$)	Lost to follow-up ($n=112$)
⩾41 years	83 (75)	104 (67)	187 (71)	85 (76)
Male sex	34 (31)	51 (33)	85 (32)	30 (27)
Living alone[a]	40 (36)	39 (25)	69 (26)	46 (41)
Not working[a,b]	56 (51)	59 (38)	112 (42)	83 (74)
Basic education	64 (58)	99 (64)	163 (62)	76 (68)
Immunomodulatory treatment[b]	45 (41)	132 (86)	177 (67)	69 (62)
Progressive MS[a,b]	60 (55)	55 (36)	115 (44)	71 (63)
Disease severity (EDSS)[a,b]				
Mild (0–3.5)	41 (37)	101 (66)	142 (54)	35 (31)
Moderate (4–6.5)	50 (45)	34 (22)	84 (32)	33 (29)
Severe (7–9.5)	19 (17)	19 (12)	38 (14)	44 (39)
Limited ambulation (0−1.2 m/s)[b]	79 (72)	58 (38)	137 (52)	65 (58)
Manual dexterity (NHPT < 0.5 pegs/s)[a,b]	52 (47)	21 (14)	73 (28)	41 (37)
Cognition (SDMT < 32 correct responses)[a]	47 (43)	56 (36)	103 (39)	55 (49)
Mood (BDI ⩾ 13 points)	20 (18)	37 (24)	57 (21)	23 (21)

MS: multiple sclerosis; EDSS; Expanded Disability Status Scale: NHPT: Nine-Hole Peg Test; SDMT: Symbol Digit Modalities Test; BDI: Beck Depression Inventory.
Data are presented as numbers (percentages).
[a]Significant differences (<0.05) between those completing the study and those dropping out of the study.
[b]Significant differences (<0.05) between the population-based and the hospital-population-based MS cohort.

Table 3. Numbers (percentages) in the mild, moderate and severe MS groups demonstrating restricted participation at baseline and 10-year follow-up, as well as classification of the change between baseline and 10-year follow-up into the following four categories: unchanged – restricted (i.e. restrictions at baseline and follow-up); declined (i.e. restrictions at follow-up but not at baseline); unchanged – no restrictions (i.e. no restrictions at baseline and follow-up) and improved (i.e. restrictions at baseline but not at follow-up).

	Not sustained participation				Sustained participation	
	Baseline	10-year follow-up	Unchanged – restricted	Declined participation	Unchanged – not restricted	Improved participation
Mild MS ($n=142$)	26 (18)	47 (33)	19 (13)	28 (20)	88 (62)	7 (5)
Moderate MS ($n=84$)	63 (75)	62 (74)	55 (65)	7 (8)	14 (17)	8 (9)
Severe MS ($n=38$)	35 (92)	36 (95)	33 (87)	3 (8)	0 (0)	2 (5)
All ($n=264$)	124 (47)	145 (55)	107 (40)	38 (14)	102 (39)	17 (6)

MS: multiple sclerosis.

OR = 8.32, $p < 0.001$) were more likely to sustain their participation than those who were limited ambulators (walking speed: 0−1.2 m/s). Also, PwMS with no impairment in manual dexterity (NHPT ⩾0.5 pegs/s, OR = 6.70, $p < 0.001$) or in cognition (SDMT ⩾32 correct responses, OR = 6.27, $p < 0.001$) were more likely to sustain their participation compared to PwMS with impairment. Sex, living situation, work status, immunomodulatory treatment and mood were not significant predictors of sustained participation ($p \geqslant 0.190$). Univariate logistic regression models for factors associated with sustained participation in complex and social everyday activities between baseline and the 10-year follow-up in people mildly, moderately and severely affected by MS at baseline are presented in Supplementary Material 3.

The multivariable logistic regression model (Table 5) showed that community ambulation status (OR = 3.58, $p = 0.001$) and no cognitive impairment (OR = 3.00,

Table 4. Participation in complex and social everyday activities assessed with the Frenchay Activities Index at baseline and at 10-year follow-up.

Variables	Mild MS ($n=142$)			Moderate MS ($n=84$)			Severe MS ($n=38$)		
	Baseline	10-year follow-up	*p* value	Baseline	10-year follow-up	*p* value	Baseline	10-year follow-up	*p* value
Domestic	13.0 (4.0)	12.0 (5.0)	**<0.001**	11.0 (6.0)	7.0 (11.7)	**<0.001**	0.5 (5.7)	0.0 (0.7)	**0.012**
Outdoors	11.0 (3.0)	10.0 (4.2)	**0.003**	7.0 (5.7)	4.0 (5.7)	**<0.001**	3.0 (5.0)	0.0 (3.0)	**<0.001**
Leisure/work	9.5 (5.0)	8.0 (6.0)	**<0.001**	6.0 (4.0)	5.0 (5.7)	**0.002**	4.0 (3.0)	2.5 (4.0)	**0.001**
Total score	33.0 (7.0)	30.0 (11.2)	**<0.001**	22.5 (11.7)	17.5 (18.0)	**<0.001**	7.5 (12.5)	3.5 (7.0)	**<0.001**

MS: multiple sclerosis.
Data are presented for the domestic, outdoor and leisure/work sub-domains and a total score, as median and interquartile range.
Bold values reflect significant change ($p < 0.05$).

$p=0.002$) remained independent predictors of sustained participation. In this model, 74.5% of the outcome was correctly classified (Nagelkerke $R^2=0.36$).

Discussion

This is the first study to explore changes in participation across 10 years in PwMS in relation to MS severity and to identify predictors of sustained participation in this population. Our results showed that the most prominent increase in participation restriction occurred in PwMS with moderate and severe MS and that independent predictors of sustained participation were community ambulation status reflected by walking speed ⩾1.2 m/s and no cognitive impairment as reflected by >32 correct responses on the SDMT. These findings accentuate the importance of developing interventions to target different domains of functioning in order to sustain long-term participation in PwMS and in particular for individuals severely affected by MS.

Changes in participation in complex and social everyday activities

Previous studies have reported inconsistent results with regard to long-term changes in participation among PwMS, varying from reduced,[10,11] sustained[6] and improved participation.[12] There is therefore no clear evidence from these studies that a certain disease group of MS would experience greater participation restrictions across time. The present findings showed that few PwMS in the moderate (26%) and severe (5%) MS groups sustained their participation as compared to 67% in the mild group. It is plausible that a small decline in functioning[5] along with a capacity to use compensatory strategies, such as personal behaviour and modification of environmental factors,[28] could have enabled greater maintenance in participation among PwMS with mild MS. In contrast, the greater decline in participation in those severely affected by MS is likely the consequence of the devastating effects of impaired physical and cognitive functioning in these subgroups.[29,30] The present findings contradict previous results by Wynia et al.[13] who reported significant decline in participation across 5 years in mild MS (EDSS 0 to <4.5) whereas no differences were observed in PwMS with severe MS. We believe that the prolonged follow-up (10 years) in our study, different measurements used and the differences in health care services between Sweden and in the Netherlands might have contributed to these varying results.

Predictors of sustained participation

In line with previous cross-sectional studies,[14–16] community ambulation status and no cognitive impairment were identified as independent predictors of sustained participation across 10 years in PwMS. These disabilities have previously been identified as predictors of sustainability of work status in PwMS.[31,32] The importance of both physical and cognitive disability for societal participation is indicative as the engagements in more complex activities require not only ambulation (e.g. walking outside) but also different cognitive abilities such as memory, attention and executive functioning. This has also been shown previously in a qualitative study by Coenen et al.[33] who reported that mobility and cognition were important for PwMS's ability to participate in work and leisure activities. In contrast to previous findings,[31] in our study manual, dexterity was a weaker predictor of participation as compared to walking ability and cognition. This deviating finding may be explained by the dependent variable of participation (FAI) in our study which addresses activities involving mobility and cognitive skills more than manual dexterity. Furthermore,

Table 5. Univariate and multiple logistic regression models for factors associated with sustained participation in complex and social everyday activities between baseline and the 10-year follow-up.

	Univariate regression		Multiple regression	
	OR (95% CI)	*p* value	OR (95% CI)	*p* value
Age				
<41 years	1.99 (1.16–3.41)	**0.012**	0.68 (0.33–1.39)	0.293
⩾41 years	1.00 (reference)		1.00 (reference)	
Sex				
Male	1.29 (0.77–2.17)	0.330		
Female	1.00 (reference)			
Living situation				
Co-habiting	1.30 (0.76–2.22)	0.330		
Living alone	1.00 (reference)			
Work status				
Working	0.99 (0.61–1.61)	0.968		
Not working	1.00 (reference)			
Education				
Higher education	1.97 (1.19–3.27)	**0.008**	1.59 (0.86–2.92)	0.136
Basic education	1.00 (reference)		1.00 (reference)	
Immunomodulatory treatment				
Treatment	0.95 (0.57–1.59)	0.837		
No treatment	1.00 (reference)			
MS type				
Relapsing MS	4.87 (2.85–8.35)	**<0.001**	1.43 (0.66–3.08)	0.367
Progressive MS	1.00 (reference)		1.00 (reference)	
Ambulation status				
Community ambulators ⩾1.2 m/s	8.32 (4.79–14.55)	**<0.001**	3.58 (1.73–7.41)	**0.001**
Limited ambulators 0–1.2 m/s	1.00 (reference)		1.00 (reference)	
Manual dexterity				
NHPT ⩾0.5 pegs/s	6.70 (3.43–13.09)	**<0.001**	2.18 (0.95–4.99)	0.065
NHPT <0.5 pegs/s	1.00 (reference)		1.00 (reference)	
Cognition				
SDMT ⩾32 correct responses	6.27 (3.53–11.16)	**<0.001**	3.00 (1.51–5.97)	**0.002**
SDMT <32 correct responses	1.00 (reference)		1.00 (reference)	
Mood				
BDI 0–12 points	1.50 (0.82–2.73)	0.190		
BDI ⩾13 points	1.00 (reference)			

OR: odds ratio; CI: confidence interval; MS: multiple sclerosis; NHPT: Nine-Hole Peg Test; SDMT: Symbol Digit Modalities Test; BDI: Beck Depression Inventory.
Bold values reflect significant change ($p < 0.05$).

although personal factors, younger age, higher education and relapsing MS, were found to be significant predictors in the univariate analyses, these factors were not independent predictors in the multivariable model. Surprisingly, and unlike previous findings,[14,34] absence of depressive symptoms was not associated with sustained participation in this study. We believe that the irregular occurrence of depressive symptoms across time in PwMS[35] and the low percentage of participants with depressive symptoms (21%) in our sample could have contributed to this variable not being detected as a significant predictor in our study.

Clinical implications and future research

The results of this study put focus on the need for health services to give support to PwMS with more severe disease to sustain participation in valued activities. This might be reached by increasing the internal capacity of

the individual to continue participation or by giving external support from the society aiming at sustained participation by compensating for mobility limitation and cognitive impairment. The current findings suggest that ambulation status and cognition could be possible targets in interventions aiming to support sustained participation in PwMS, preferably early in the trajectory of the disease. Furthermore, it is important to empower PwMS to self-management early in the disease course and to provide specific interventions within multi-disciplinary rehabilitation programmes which address these areas of functioning in an integrated manner. An approach with focus on both cognition and mobility would likely be of specific importance for long-term gains in participation in PwMS as restrictions in complex and social everyday activities seem to derive from a combination of motor and cognitive disabilities.

Methodology considerations

This study has some methodological issues that require consideration. First, we combined data from two MS cohorts in Stockholm, Sweden[8,17] in order to explore changes in participation in a larger sample than previous studies and thereby also increase the statistical power. The population-based cohort demonstrated greater disease severity and overall disability than the outpatient-based cohort. These differences might have been the result of increased possibilities for specialist care in the outpatient-based cohort which is supported by the high proportion (86%) receiving immunomodulatory treatment in the outpatient-based cohort. Nevertheless, we believe that these cohorts combined better reflect the diversity of PwMS receiving healthcare in the Stockholm region. Second, compared to those completing the study, a larger proportion of those dropping out from the study were older, lived alone, were not working and had more severe MS and an overall more severe disability profile. It is therefore possible that our results may have underestimated the true changes in participation restrictions in PwMS across 10 years. Third, the list of predictor variables identified in this study contribute but cannot explain all of the variation of changes in participation and other predictors need to be further explored, such as fatigue, bladder impairment, quality of life, specific information about work status (e.g. part- and full-time work) and adaptive processes such as coping strategies. Long-term changes in participation might also be a result of stressful or other life events covering personal domains that are difficult to capture in quantitative studies. It is also worth noticing that MS disability as measured by the EDSS was not included in the regression analyses given its known collinearity with walking ability. While the SDMT measures one domain of cognition (processing speed), other cognitive domains (e.g. executive functions) might also be associated with long-term changes in participation in PwMS. Finally, the concept of participation is still debated. In this study, we defined participation as performance of more complex activities in societal contexts requiring the initiative from the individual and we used the FAI to study participation. Although the FAI has been widely used to assess participation in social/lifestyle activities in PwMS,[6,8,15,17] it is a self-reported measure which may be influenced by self-perceptions being prone to recall bias. Participants could also have been active in domains not covered by FAI (e.g. social contacts and daily life by using the Internet).

Conclusion

Prominent long-term increases in participation restrictions occurred across the spectrum of MS severity, but the overall decline was largest among PwMS with severe MS. The large increase in participation restrictions in PwMS accentuates the importance for health services to support mobility and cognitive function to obtain sustained participation.

Declaration of Conflicting Interests

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Supplemental material

Supplemental material for this article is available online.

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