



Self-assessment reliability in multiple sclerosis: the role of socio-demographic, clinical, and quality of life aspects

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Abstract

Introduction Several multiple sclerosis studies matching self- and physician assessment of disease course and disability show moderate and high agreement respectively. However, the role played by socio-demographic, clinical, and quality of life (QoL) factors was not much investigated. The study aims at exploring how self-/physician agreement could depend on these variables.

Materials and methods Participants were asked to report own disease course and disability according to preset categories. Kappa-value and confidence interval (CI) for disease course and two-way random interclass correlation coefficient (ICC) and CI for disability were calculated to evaluate self-/physician agreement. X^2 was applied to examine whether other factors (gender, age, education, civil status, disease duration, fatigue, quality of life) had systematic effects.

Results Data analysis on 203 participants indicated fair agreement (Kappa-value = 0.30; 95% CI 0.23–0.38) and no dependency on the categories of each variable for disease course. Satisfactory correlation was found for disability (ICC = 0.74; 95% IC 0.67–0.80), good agreement was found for almost all variable categories, and significant differences were observed for education (better agreement for higher levels), disease duration, fatigue and QoL (better agreement for worse conditions).

Discussion Results seem to suggest that higher education and worse clinical and QoL conditions could engage the patient in developing more disease awareness and realistic self-perception and self-evaluation.

Keywords Self-assessment · Disease course · Disability · Multiple sclerosis

Introduction

Disease course and disability self-assessment in multiple sclerosis (MS) is crucial in clinical and non-clinical trials as a proxy of decline trajectories, treatment responsiveness, research studies dropout motivations, and other relevant variables. Several studies evaluated the possible differences between disease course [1] and disability [2, 3] self- and physician report, the latter considered as gold standard. The main results showed moderate agreement for disease course; people with MS (PwMS) classified themselves with a worse form than the physician report [1]. Conversely, disability showed higher agreement and, consequently, was considered a more reliable self-reported measure [4]. After all, self-reported

disease course may be biased by what the neurologist last told the patient in clinic and he/she actually had understood and remembered [1], whereas self-reported disability depends on the capacity to self-perceive and self-evaluate own physical status. Despite the relevance of these two self-reported information, a little is known about the role played by factors that could influence the self-/physician agreement.

The study aims at exploring how disease course and disability self-/physician agreement could depend on socio-demographic, clinical, and quality of life (QoL) factors.

Materials and methods

Recruitment occurred among patients followed at the Italian Multiple Sclerosis Society Rehabilitation Centers of Genoa, Padua, and Vicenza. Study procedures followed the Declaration of Helsinki (1964); we obtained ethical approval from the Regional Ethics Committee, Liguria, Italy (023REG2014). Informed content was obtained from all the participants. They filled an ad-hoc questionnaire in which their own current disease course was self-reported according

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to four standard categories: relapsing-remitting (RR), progressive relapsing (PR), secondary (SP), and primary progressive (PP), shortly defined on a sheet to provide more validity to the study (i.e., “progressive worsening without attacks - primary progressive”). Moreover, participants evaluated their own current disability level using the self-Expanded Disability Status Scale (self-EDSS) [5].

Other outcomes were collected: gender, age, education, civil status (i.e., socio-demographic), disease duration, fatigue visual analogue scale (F-VAS) (clinical), and the European Quality of Life Five Dimensions (EQ-5D-3L) (QoL). F-VAS score was stratified in mild (<30), moderate (30–69), severe (≥ 0.70). EQ-5D-3L in poor (<0.50), fair (0.50–0.74), good (≥ 0.75). The neurologist of each patient was contacted to assess disease course and EDSS within the 2 weeks around the questionnaire compilation.

To evaluate the self-/physician agreement for the disease course categorical variable, we calculated the Kappa-value and the related confidence interval (CI) using bootstrap method performing 1000 repetitions. Qualitative Kappa-value agreement descriptions were 0.81–1.0 = “almost perfect,” 0.61–0.80 = “substantial,” 0.41–0.60 = “moderate,” 0.21–0.40 = “fair,” 0.0–0.20 = “slight.” To evaluate the self-/physician agreement for the disability ordinal variable, we calculated the two-way random interclass correlation coefficient (ICC) and the related 95% CI. ICC could be poor (<0.7), satisfactory (0.7–0.9), and good (>0.9). Kappa-value and

ICC with 95% CI were analyzed within different subgroups. We dichotomized data into full agreement vs. no agreement for disease course and full agreement (or agreement within ± 1.0) vs. no agreement for EDSS. Thus, we performed X^2 test to examine whether socio-demographic, clinical, and QoL variables had systematic effects on self-/physician agreement. Statistical analysis was performed using Stata 13 (Stata Corp, College Station, TX).

Results

We recruited 203 PwMS. Only 188 participants completed the clinical course part: 44 classified themselves as RR, 26 PR, 64 PP, and 54 SP. The corresponding physician assessment revealed 85 RR, 6 PR, 14 PP, and 83 SP individuals. Data analysis indicated fair agreement for the whole cohort (Kappa-value = 0.30; 95% CI 0.23–0.38). The 48.4% (91/188) of patients agreed with physician, 43.6% reported themselves worst, and 8.0% better. RR and PR PwMS were the most disagreed (55.3% and 66.7% respectively) stating themselves with a more severe disease course. As expected, subgroup analysis showed fair agreement for all categories of each variable (except for single civil status and good QoL reaching moderate agreement) and no significant differences were found (Table 1).

Table 1 Disease course self-/physician agreement

Variable	Categories	n	Kappa statistic (CI 95%)	Agreement	Worst	Better	^a P value
All		188	0.30 (0.23–0.38)	48.4%	43.6%	8.0%	
Gender	Male	59	0.27 (0.14–0.45)	47.5%	44.1%	8.5%	0.861
	Female	129	0.30 (0.21–0.42)	48.8%	43.4%	7.8%	
Age	< 45 years	67	0.23 (0.14–0.34)	55.2%	43.3%	1.5%	0.164
	≥ 45 years	121	0.36 (0.22–0.50)	44.6%	43.8%	11.6%	
Education	University degree	29	0.40 (0.23–0.63)	55.2%	44.8%	0.0%	0.082
	High school	83	0.38 (0.26–0.50)	55.4%	36.1%	8.4%	
	Primary school	75	0.18 (0.06–0.30)	38.7%	52.0%	9.3%	
Civil status	Single	27	0.46 (0.25–0.68)	63.0%	37.0%	0.0%	0.158
	Married/living together	128	0.25 (0.16–0.35)	43.8%	46.1%	10.2%	
	Separated/Divorced/Widower	30	0.36 (0.15–0.58)	53.3%	40.0%	6.7%	
Disease duration	≤ 10 years	53	0.34 (0.20–0.51)	56.6%	37.7%	5.7%	0.210
	11–19 years	73	0.23 (0.12–0.35)	41.1%	53.4%	5.5%	
	≥ 20 years	59	0.23 (0.09–0.39)	50.9%	35.6%	13.6%	
F-VAS	Mild (<30)	25	0.29 (0.08–0.51)	48.0%	48.0%	4.0%	0.991
	Moderate (30–69)	55	0.32 (0.17–0.46)	49.1%	40.0%	10.9%	
	Severe (≥ 70)	95	0.30 (0.19–0.42)	49.5%	44.2%	6.3%	
EQ-5D-3L	Poor (<0.50)	55	0.28 (0.15–0.43)	47.3%	40.0%	12.7%	0.227
	Fair (0.50–0.74)	91	0.26 (0.16–0.39)	46.1%	47.3%	6.6%	
	Good (≥ 0.75)	28	0.48 (0.27–0.74)	64.3%	35.7%	0.0%	

^a P value on agreement status

Only 192 participants completed the disability part. Data analysis showed a satisfactory self-/physician correlation in EDSS (ICC = 0.74; 95% IC 0.67–0.80). The 78.7% (151/192) of patients agreed with physician (35.4% full agreement; 43.3% agreement within ± 1.0 point), while the remaining declared a lower disability. Subgroup analysis showed satisfactory agreement for almost all categories of each variable. Statistically significant differences were observed for education, disease duration, F-VAS, and EQ-5D-3L ($p < 0.05$) (Table 2); the agreement increased with higher education levels, worse clinical predictor and lower QoL.

Discussion

As previously reported, disease course was showed to be a not so reliable self-reported measure and this result seemed to not depend on socio-demographic, clinical, and QoL factors. As expected, disability was more reliable, although depending on some other factors. Higher education levels are associated to better self-management and, consequently, could lead to develop more disease awareness and improve the capacity to correctly self-evaluate the disability [6].

The agreement was higher at middle and longer disease durations, when PwMS probably become more aware in facing MS and easier perceive also slight worsening in their daily activity performances consequently maturing

a more accurate ability to self-perceive own physical status [7]. Also, at lower disease duration, worsening mainly due to relapses and recovery due to remissions, rehabilitation, and pharmacological treatments could require a continuous recalibration in self-perceiving own physical status consequently leading to incorrect estimations of the disability level.

Disease self-management could explain the disability agreement due to fatigue. Severe disability levels likely induce to adopt more active self-management strategies to preserve physical resources; the attention for own physical status could increase and, consequently, improve disability self-evaluation. Conversely, at mild and moderate fatigue levels, the patient may feel less disabled than he/she actually is [6, 7] or experience the fatigue-motor performance paradox [8]; it may result in an under- or over-estimation of the disability level.

Finally, the self-/physician disability agreement significantly increased with QoL decrement [7]. Poorer QoL may induce PwMS to perceive more narrowly the disease symptoms and to provide more correct disability self-assessment.

In conclusion, the self-/physician agreement was more reliable for disability than disease course. Higher education levels and worse clinical and QoL conditions could engage the patient in developing more disease awareness and realistic self-perception and self-evaluation.

Table 2 Disability self-/physician agreement

Variables	Categories	<i>n</i>	ICC (IC 95%)	^a Mean difference	% Full agreement or within ± 1.0 point	^b <i>P</i> value
All		192	0.74 (0.67–0.80)	+ 0.49	78.7%	
Gender	Male	62	0.68 (0.55–0.81)	+ 0.27	80.7%	0.641
	Female	130	0.74 (0.67–0.82)	+ 0.60	77.7%	
Age	< 45 years	64	0.76 (0.66–0.86)	+ 0.58	79.7%	0.803
	≥ 45 years	128	0.69 (0.60–0.78)	+ 0.45	78.1%	
Education	University degree	30	0.80 (0.67–0.93)	+ 0.70	80.0%	0.011*
	High school	82	0.87 (0.81–0.92)	+ 0.27	87.8%	
	Primary school	79	0.51 (0.34–0.67)	+ 0.65	68.4%	
Civil status	Single	26	0.79 (0.65–0.94)	+ 0.60	80.8%	0.466
	Married/living together	133	0.74 (0.66–0.81)	+ 0.44	76.7%	
	Separated/divorced/widower	30	0.66 (0.46–0.86)	+ 0.65	86.7%	
Disease duration	≤ 10 years	52	0.60 (0.43–0.78)	+ 0.63	61.5%	0.001*
	11–19 years	76	0.79 (0.71–0.88)	+ 0.51	86.8%	
	≥ 20 years	61	0.70 (0.57–0.83)	+ 0.30	83.6%	
F-VAS	Mild (< 30)	25	0.75 (0.57–0.92)	+ 0.70	76.0%	0.007*
	Moderate (30–69)	97	0.52 (0.32–0.71)	+ 0.82	64.9%	
	Severe (≥ 70)	57	0.85 (0.79–0.90)	+ 0.29	86.6%	
EQ-5D-3L	Poor (< 0.50)	56	0.85 (0.78–0.92)	+ 0.23	89.3%	0.029*
	Fair (0.50–0.74)	96	0.66 (0.54–0.77)	+ 0.67	75.0%	
	Good (≥ 0.75)	26	0.60 (0.36–0.85)	+ 0.60	65.4%	

^a Mean difference calculated on self-/physician EDSS differences. ^b *P* value on agreement status. * significance level for $P < 0.05$.

However, the lack of variables such as employment status, financial income, and living area [9] as potential predictors as well as of a more comprehensive evaluation of the participants (e.g., through the ICF core set) [10] is a limitation of the study.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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