Psychometric properties of a Patient Reported Outcome Measure (PROM) evaluating patient autonomy in Multiple Sclerosis (MS)

Mekies C(1), Cohen M(2), Mouzawak C(3), Paillot G(4), Brechenmacher L(5), Montagu G(6), Civet A(7), Nevoret C(8), Berdeaux G(9), Pau D(7), Donze C(10)

(1) Neurologie, RAMSAY clinique des Cèdres, Toulouse, France ; (2) Neurologie, URRIS, Unité de Recherche Clinique Cote d'Azur-UR2CA-CRCSEP, Hôpital Pasteur, France ; (3) Réseau SEP IDF ouest, Hôpital du Vésinet, Le Vésinet, France ; (4) Association Aventure Hustive, Saint-Malo, Département Universitaire des Patients Grenoble Alpes, Grenoble, France ; (5) Affaires médicales, Roche SAS, Boulogne-Billancourt, France ; (6) Recherche, Unknowns SAS, Paris, France ; (7) Medical Data Center, Roche SAS, Boulogne-Billancourt, France ; (8) CEMKA, Bourg-La-Reine France ; (9) Santé Publique, Berdeaux Consulting SAS, Lacanau, France ; (10) Faculté de médecine et de maïeutique de Lille, Hôpital Saint Philibert, Lille, France

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Introduction

Multiple sclerosis leads to neurological symptoms and accumulating disability that can threaten patient's autonomy (1,2). Current tools that assess these impacts (EDSS) multiple sclerosis impact scale 29 [MSIS-29] have their limits and do not allow to assess a social impact of the disease symptoms.

In collaboration with patient associations, the project aimed at developing a self-assessment tool including the impact of MS on social dimension to facilitate communication between the patient and doctor for a better monitoring and care management of the patient.

Project objective:

This study aimed to evaluate the psychometric properties of a PROM dedicated at identifying the social disabilities / autonomy of patients with MS.

Methods

The psychometric validation of the questionnaire evaluating patient autonomy in multiple sclerosis (MS) has been performed by empirically validating the initial theoretical conceptual model composed of 131 questions clustered in 13 social dimensions targeting a 36-items short form.

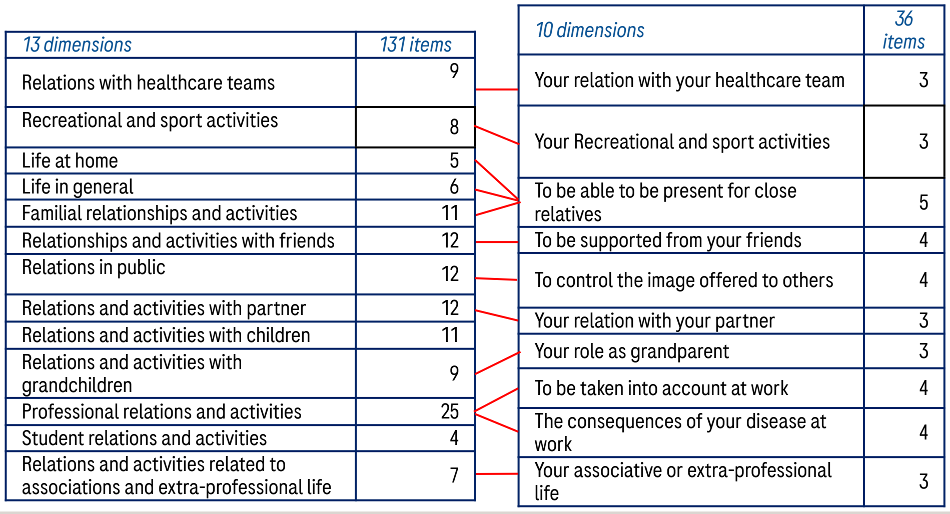
Validity. as well as reduction of the number of items and modalities were presented at previous conferences (3)(4).

Construct validity of the reduced questionnaire has been evaluated using ANOVA with class on disease severity proxy estimated using the SymptoMScreen questionnaire, results are displayed in this poster.

Questionnaire dimensions reduction

Apart from student relationships and activities concerning too few patients (only 10 dimensions taken into account in further analysis), all social roles defined in the initial 131-item questionnaire were considered important by the patients. Table 1 below displays the reduction of the number of items and modalities.

Table 1. From initial to final questionnaire



13 dimensions	*131 items*
Relations with healthcare teams	9
Recreational and sport activities	8
Life at home	5
Life in general	6
Familial relationships and activities	11
Relationships and activities with friends	12
Relations in public	12
Relations and activities with partner	12
Relations and activities with children	11
Relations and activities with grandchildren	9
Professional relations and activities	25
Student relations and activities	4
Relations and activities related to associations and extra-professional life	7

10 dimensions	*36 items*
Your relation with your healthcare team	3
Your Recreational and sport activities	3
To be able to be present for close relatives	5
To be supported from your friends	4
To control the image offered to others	4
Your relation with your partner	3
Your role as grandparent	3
To be taken into account at work	4
The consequences of your disease at work	4
Your associative or extra-professional life	3

Results

Of the 708 patients who completed the initial questionnaire. 653 (92%) were more than 80% complete (analyzable population - Table 2).

Table 2: Characteristics of the analyzable population according to the severity of the disease (SymptoMScreen score)

Patient's characteristics	*SymptoMScreen <25 (N=314)*	*SymptoMScreen [25-48] (N=310)*	*SymptoMScreen >48 (N=29)*	*Overall (N=653)*
Sex				
Female	268 (85.6%)	253 (81.9%)	23 (79.3%)	544 (83.6%)
Male	45 (14.4%)	56 (18.1%)	6 (20.7%)	107 (16.4%)
Age in 2022 (years)				
<30	31 (9.9%)	14 (4.5%)	1 (3.4%)	48 (7.4%)
[30 - 40[	92 (29.4%)	66 (21.4%)	2 (6.9%)	160 (24.5%)
[40 - 50[	103 (32.9%)	93 (30.1%)	2 (6.9%)	198 (30.3%)
[50 - 60[	62 (19.8%)	94 (30.4%)	11 (37.9%)	167 (25.6%)
≥60	25 (8.0%)	42 (13.6%)	13 (44.8%)	80 (12.3%)
Duration of MS (years)				
<5	112 (35.9%)	90 (29.2%)	3 (10.3%)	209 (32.0%)
[5 - 15]	128 (41.0%)	130 (42.2%)	14 (48.3%)	272 (41.7%)
>15	72 (23.1%)	88 (28.6%)	12 (41.4%)	172 (26.3%)
Quasi constant mobility assistance required	31 (9.9%)	81 (26.3%)	22 (75.9%)	134 (20.6%)

Construct validity

The construct validity was evaluated using an ANOVA to estimate the relation between the reduced questionnaire dimension scores and the disease severity classes (Table 2) assessed by the SymptoMScreen questionnaire.

Table 3 below displays for each dimension the associated correlation. The higher the score for a dimension, the higher is the burden, except for 2 dimensions: *Recreational and sport activities / To be able to be present for close relatives*, where lower scores are associated with higher burden.

Correlations were strong ($p<0.05$) for 5 out of 6 of the general dimensions (in blue), whereas specific dimensions (1 out of 4 dimensions, in green) were less correlated.

Increased disease symptoms (greater SymptoMScreen score) are associated with less participation of patients to personal, professional activities or medical decisions regarding their disease: recreational and sport activities, to be able to be present for close relatives, to control the image offered to others, consequences of your disease at work, role as grandparent, relations with healthcare teams.

Level of support from others (at home or at work) are not associated with disease symptoms: Your relation with your partner, to be supported from your friends, to be taken into account at work, associative or extra-professional life.

This confirms the construct validity of the final questionnaire.

Table 3: Association between SymptoMScreen and PROM dimensions

Mean (SD) dimension score	SymptoMScreen <25 (N = 314)	SymptoMScreen [25-48] (N = 310)	SymptoMScreen >48 (N = 29)	P-value
Relations with healthcare teams	4.22 (1.33)	3.82 (1.36)	4.38 (1.26)	0.0004
Recreational and sport activities	3.68 (1.65)	3.02 (1.61)	2.53 (1.51)	<0.0001
To be able to be present for close relatives	4.42 (0.97)	3.4 (0.96)	2.61 (0.98)	<0.0001
To be supported from your friends	3.45 (1.07)	3.58 (1.1)	3.66 (1.3)	0.261
To control the image offered to others	2.14 (1.05)	2.91 (1.24)	2.86 (1.28)	<0.0001
Your relation with your partner	4.05 (1.12)	4.19 (1.17)	3.88 (1.37)	0.32
Your role as grandparent	4.68 (1.49)	3.56 (1.62)	3.2 (1.87)	0.0043
To be taken into account at work	4.03 (1.43)	3.9 (1.66)	5.27 (1.28)	0.126
The consequences of your disease at work	2.84 (1.37)	3.83 (1.39)	4.53 (1.52)	<0.0001
Your associative or extra-professional life	4.25 (1.45)	3.99 (1.49)	4.14 (1.11)	0.408

Conclusion

The population included in the study covers the different profiles of MS patients and is close to the epidemiology described by the French Health Insurance and the French MS Observatory (OFSEP).

The reduction of the dimensions and questions allowed the construction of a 10-dimensional questionnaire with 36 questions in total.

Construct validity has shown the social impact of the disease symptoms: increased disease symptoms (greater SymptoMScreen score) are associated with less participation of patients to personal or professional activities, but not associated with level of support from others.

Results support the use of the PROM to evaluate the autonomy of patients suffering from MS. This 36-question questionnaire will now be tested during consultations between health professionals and patients, in order to validate its psychometric properties.

References:
(1) Kappos L. et al. JAMA Neurol 2020;77(9):1132-40
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(3), (4) EPICLIN 2023, EAN 2023

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