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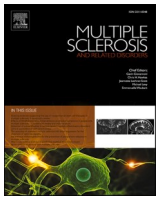

Original article

Development of a new patient-reported outcome measure for patients with multiple sclerosis: the Multiple Sclerosis Autonomy Scale (MSAS)

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ABSTRACT

Background: In multiple sclerosis (MS), the measure of the loss of autonomy appears to be particularly relevant to provide adapted and personalized responses to improve the quality of care in routine clinical practice. In this context, this research aimed to develop a new patient-reported outcome measure (PROM) evaluating MS patients' autonomy, in order to provide an easy-to-use tool in the context of the relations between healthcare professionals and patients with MS, and to be used in future clinical trials for treatment assessment.

Methods: This research was conducted in two consecutive stages. First, a preliminary questionnaire was generated using an innovative sociological approach for MS (after literature review, patient interviews, experts' opinion, and patient focus groups). This questionnaire was then completed by patients with MS, before the reduction of the scale while maintaining relevant information, using a principal component analysis. The internal consistency reliability was assessed using the Cronbach's alpha coefficient. The external validity was evaluated using an analysis of variance to estimate the relation between the reduced questionnaire dimension scores and disease severity classes assessed by the SymptoMScreen questionnaire.

Results: The first qualitative step of the research led to provide a definition of disease-related autonomy as perceived by patients (to be able to carry out the roles the patient thinks the most important whether or not he/she receives assistance) as well as an associated taxonomy. On this basis, a preliminary questionnaire of 131 items grouped into 13 social dimensions was generated (seven dimensions with 63 questions concerning all the patients, and six dimensions with 68 questions concerning specific patients). This questionnaire was completed on a web platform by 653 analyzable patients with MS. Their main characteristics were as follows: female patients: 83.6 %, mean age at MS diagnosis: 34.8 ± 10.5 years, age ≥40 years at data collection: 68.1 %, MS duration ≥5 years: 68.4 %, severe MS (SymptoMScreen score ≥30): 36.8 %. On the basis on completed 131-item questionnaires, it was reduced in a 36-item short form of 10 social dimensions (five dimensions with 19 questions concerning all the patients, and five dimensions with 17 questions concerning specific patients). The internal consistency of the final questionnaire was good for all the dimensions, as the Cronbach's alpha coefficient ranged from 0.77 to 0.85 depending on dimensions. The construct validity of the questionnaire was also confirmed.

Conclusion: Our research allowed to build the first PROM designed to evaluate the autonomy of patients suffering from MS: the Multiple Sclerosis Autonomy Scale (MSAS). A confirmatory study, conducted in patients with MS using this validated questionnaire, is currently conducted.

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1. Introduction

Over the past 20 years, there has been a growing interest in better insight into patient perception to evaluate outcomes that matter most to patients. This is particularly relevant in multiple sclerosis (MS), a chronic and disabling neurological condition affecting mostly young people. Several scales were then developed to specifically assess the impact of the disease on daily activities and quality of life of patients with MS (PwMS), notably to provide valuable insight into treatment benefits and quality of care (Food and Drug; European Medicines Agency. Doc. Ref. EMEA/CHMP/EWP/139391/2004, 2005; Autorité de santé, 2021) (Multiple Sclerosis International Quality of Life Questionnaire, MusiQoL (Simeoni et al., 2008); SymptoMScreen (Fitzgerald et al., 2019), Multiple Sclerosis Impact Scale, MSIS-29 Eagly and Wood, 1987, etc.). However, these scales do not assess the notion of social contextualization of life with MS. Moreover, disability accumulation in relapsing MS, the most frequent form of the disease, is not always associated with overt relapses and symptoms (Kappos et al., 2020). In addition, available scales do not suggest possible actions based on the results they offer. Therefore, there is a need for extending PwMS management to fully acknowledge the disease burden on their activities of daily living (ADL) that can lead to a loss of autonomy. In this context, the development of a new Patient-Reported Outcome Measure (PROM) focused on autonomy could help PwMS to have a better understanding of their own disease, to faster identify the most important MS impact on their daily life, and thus to help communication with healthcare professionals when reporting on autonomy. Such PROM might be used to provide adapted and personalized responses and improve quality of care in routine clinical practice (Entwistle et al., 2010), as well as to be usefully integrated in future clinical trials for treatment assessment. The objective of the research was to build a short patient centered questionnaire to leverage discussion with their healthcare team. We present here the development and validation of a new PROM, the Multiple Sclerosis Autonomy Scale (MSAS), focused on the autonomy of PwMS.

2. Materials and methods

2.1. Overview

This research was conducted in collaboration with French MS patients' associations.

The French MSAS questionnaire was developed in two consecutive stages. First, a preliminary 131-item questionnaire comprising 13 social dimensions was built after literature review, 12 experts' opinions, 20 patient interviews, and four patient focus groups for validation, according to guidelines for qualitative researches (Tong et al., 2007; O'Brien et al., 2014). This questionnaire was completed online using a secured website platform (MoiPatient) by 708 PwMS. Usual psychometric validation methods were then used to develop a reduced 36-item scale measuring 10 dimensions, and construct validity of the final PROM was assessed. This process is in accordance with the recommendations of the Food and Drug Administration for the development of PROMs (Food and Drug).

The qualitative phase of the study, in the field of social sciences in healthcare, complied with the European General Data Protection Regulation (GDPR) and the French MR-004 reference method. Data collected as part of the quantitative phase of the research respected the principle of minimization (collection of data strictly necessary and relevant to the objectives of the research) and complied with the GDPR and French MR-003 reference method; the study protocol was approved on June 28, 2022 by the independent "*Sud-Est III*" Ethics Committee (reference number: 2022-A01169-34).

2.2. First step: generation of the preliminary questionnaire

The steps of the qualitative phase (Cohen et al., 2022; Mekies et al., 2022; Donzé et al., 2022) aiming to develop the preliminary questionnaire concerning the MS impact on patient autonomy is presented in the Fig. 1. This questionnaire was generated from three sources: a comprehensive literature review performed in January 2020, 12 interviews with healthcare professionals and social workers involved in PwMS management (November 2020–January 2021), and 20 semi-structured phone interviews with PwMS representative of the diversity of the disease (November 2020–January 2021). These PwMS interviews, conducted by a sociologist using ethnographic methods, lasted 1–1.5 h, were tape-recorded, transcribed, and analyzed by two sociologists according to the principles of grounded (Mead, 2015) and social role (Eagly and Wood, 1987) theories. Verbatims related to patient autonomy were extracted from interviews, grouped into themes and examined for redundancy. A total of 1580 extracted verbatims generated 199 analysis items that were transposed into 131 questions grouped into 13 social dimensions. For each autonomy dimension, the first question assessed the importance of the topic, using a 10-point rating scale; the following questions evaluating the impact level of each item on the patient were based on 6-point Likert scales (Cox, 1980; Miller, 1956) expressed in frequency or intensity, and depending on the wording of each question (from never to all the times; from strongly disagree to strongly agree; from not at all to quite). The understanding, the pertinence and the answering feasibility of the preliminary questionnaire was checked through four focus groups involving three patients each. It was finalized in July 2021.

2.3. Second step: field test and questionnaire reduction

Eligible patients interested to participate completed the preliminary 131-item questionnaire online, using a patient-related platform (MoiPatient), together with sociodemographic and medical questions (age at inclusion and at MS diagnosis, gender, comorbidities impacting ADL, quasi-constant mobility assistance required, history of a significant event that impacted ADL) as well as the 12-item SymptoMScreen scale (Hobart et al., 2001). The completion of 131-item questionnaire did not exceed 90 min, and it had to be completed within one week after the first answer was provided. Eligible patients were adult PwMS (age $\geq$18 years) having an internet connection, and able to fill out the questionnaire on their own. Patients with another neurological disease (Alzheimer's or Parkinson's disease, neuromyelitis optica spectrum disorder, or myelin oligodendrocytes glycoprotein antibody disease), not reading French or not fluent in French, and/or persons of legal age protected by law could not participate.

The total population included all eligible patients who completed at least one item of the preliminary questionnaire, and the analyzable population comprised all eligible patients who fulfilled at least 80 % of the items (questions). Patient profile and dimensions of the preliminary questionnaire were described in the analyzable population, globally and according to SymptoMScreen classes ($<$30 *versus* $\geq$30; $<$25, [25-48], and $>$48), using standard descriptive statistics. Given our study sample size and advice from MS experts, we hypothesized that less than 10 % of patients would answer extreme values, reason why we chose a 10 % threshold to detect floor and ceiling effects, using the percentage of low or high responses within the importance scale of each dimension. To confirm the conceptual model (number of dimensions and related items), analysis of correlation matrices (parametric and non-parametric) and results of a principal component analysis with varimax rotations were used. Item reduction and internal consistency of the questionnaire were studied using methods such as the Cronbach's alpha coefficient and Backward Cronbach Alpha Curves (BCAC) (Mesbah, 2012). Unidimensional item reduction was an iterative process, one item removed at a time, models were re-estimated accordingly. Reliability of the final model has been evaluated using Expected A Posteriori (EAP) and Weighted Likelihood Estimator (WLE) reliability estimates (Adams, 2005). Multitrait analysis was also conducted by evaluating, during the item reduction process, the correlation of each item with their own scale

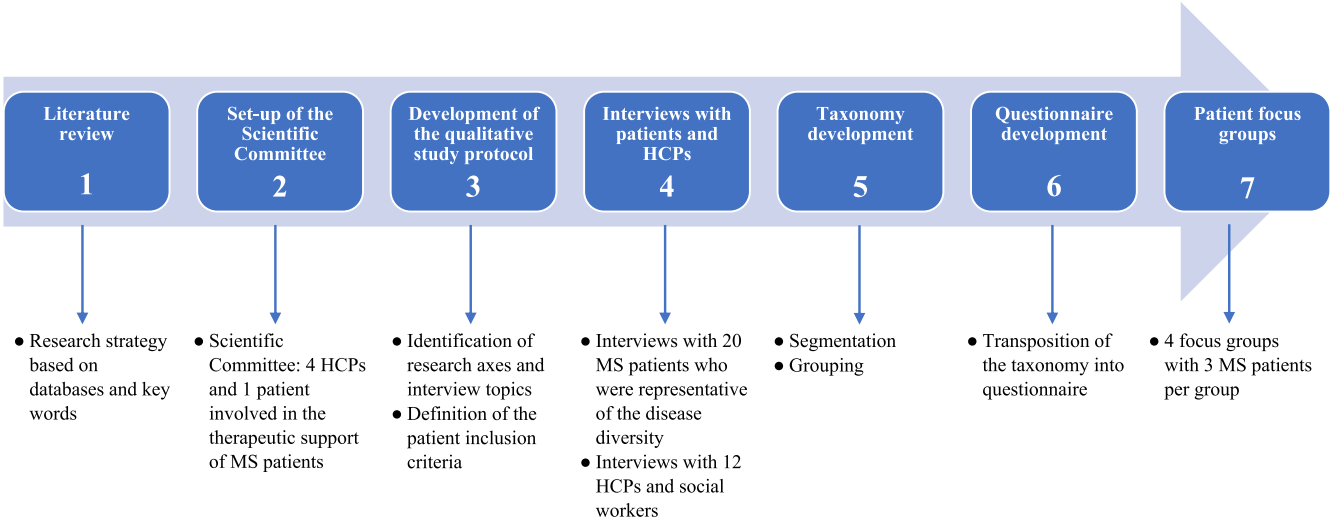

Fig. 1. Steps of the qualitative phase of the research physical and rehabilitation medicine, and one nurse.
HCP, healthcare professional; MS, multiple sclerosis. The Scientific Committee of the study comprised the following four HCPs: two neurologists, one specialist of physical and rehabilitation medicine, and one nurse.

score, other scale scores. All steps of analysis and results are available in the Supplementary materials 1 to 7. Construct validity of the reduced questionnaire was evaluated using the analysis of variance (ANOVA) with the disease severity proxy (*i.e.,* the SymptoMScreen classes).

Statistics were carried out using SAS® software (SAS Institute, North Carolina, USA), version 9.4, and R software (version 4.2.1).

2.4. Sample size

As a minimal number of 5 patients answering to each question was required to empirically ensure a stable rotation, and assuming a proportion of 90 % of patients having completed 80 % of the questions, around 725 patients had to participate in this step of the research.

3. Results

3.1. Descriptive analysis

The 20 PwMS initially interviewed during the qualitative phase of the research (Fig. 1) were representative of the disease diversity (Table 1).

A total of 708 MS patients completed at least one question of this questionnaire (total population) between July and December 2022. Among them, 653 patients (92.2 %) fulfilled at least 80 % of the questions (analyzable population) with no differences regarding their main characteristics (Table 3).

For these 653 patients, the number of missing data was limited: 13 patients (2.0 %) did not respond to at least one question; few missing data were observed per patient; few patients answered they were not concerned by a question within a specific dimension. In addition, floor effects (<10 %) were marginally present. Overall, 240 patients (36.8 %) of the analyzable population suffered from severe MS (SymptoMScreen score ≥30) (Table 4).

A total of 314 patients (48.1 %) had a SymptoMScreen score less than 25, 310 patients (47.5 %) a score within the range of 25–48, and 29 patients (4.4 %) a score higher than 48. Most patients were female (83.6 %), and patient mean age at MS diagnosis was 34.8 ± 10.5 years. At the time of data collection, 68.1 % of patients were aged at least 40 years, and MS lasted for at least 5 years in 68.4 % of the cases. Severe patients (SymptoMScreen score ≥30) were significantly ($p < 0.05$) older than others at the time of data collection (mean age: 48.8 ± 11.8 *versus* 44.3 ± 11.1 years) and at MS diagnosis (36.0 ± 11.1 *versus* 34.1 ± 10.1 years), suffered from MS for longer (median duration, IQR: 10.0, 4.0–19.0 *versus* 8.0, 3.0–15.0 years), required quasi-constant walking assistance device more often (36.0 % *versus* 11.7 %), had other comorbidity(ies) impacting their daily activities more often (25.5 % *versus* 10.5 %), and experienced a significant event impacting MS more often over the past 4 weeks (40.3 % *versus* 21.1 %).

Table 5 describes the number of patients concerned by each of the six dimensions related to specific patients.

Table 1
Characteristics of the patients interviewed – Qualitative phase of the research.

Patient characteristics	Total ($N = 20$) (n, %)
Male patients - n (%)	9 (45)
Age (years) – median (range)	51.5 (21-70)
Age at multiple sclerosis diagnosis (years) – median (range)	38.5 (18-58)
Duration of multiple sclerosis (years) – median (range)	12 (1-41)
Presence of caregiver - n (%)	13 (65)
Professional activity - n (%)	
Employee – dominance of intellectual activities	12 (60)
Employee – dominance of manual activities	4 (20)
Self-employed – dominance of intellectual activities	2 (10)
Self-employed – dominance of manual activities	2 (10)
Motor disability stated - n (%)	
Wheelchair	3 (15)
Working difficulties (with assistance)	7 (35)
Working difficulties (without assistance)	2 (10)
No visible disability	8 (40)
MSIS -29	
Physical subscale (0–100) – median (range)	33 (4-65)
Psychological subscale (0–100) – median (range)	36 (0-69)

MSIS, Multiple Sclerosis Impact Scale

The 131 items of the preliminary questionnaire generated after this research phase were grouped into 13 social dimensions (seven dimensions with 63 questions concerning all the patients, and six dimensions with 68 questions concerning specific patients) (Table 2).

3.2. Reduction of the preliminary questionnaire

A principal component analysis was performed to reduce the number of dimensions by grouping all variables (questions) through extracting their commonalities in a smaller number of factors (axes). For this

analysis, the following questions were excluded: items related to the importance accorded by patients to each dimension, questions related to student roles, questions with Yes/No answers for the four other dimensions related to specific patients (living with a partner, to be parent, to be grandparent, to work, and to participate in an association). After the exclusion of these items, 115 homogenous questions were used for analysis (6-point Likert scales). On this basis, ten axes with 50.8 % of the explained inertia were retained. For a given variable, the contributions to each of the 10 axes were studied, and the variable was associated with the dimension for which its contribution was the highest. For each axis, variables were then selected using criteria such as deletion within a dimension of items with a low contribution to the dimension in question or selection of items that were consistent within the dimension in question, while retaining sufficient information. Finally, a reduced questionnaire was generated, including 36 items grouped into 10 dimensions (including 10 items related to the importance accorded by patients to each dimension). This final questionnaire comprised five dimensions with 19 questions concerning all the patients, and five dimensions with 17 questions concerning specific patients (Table 2). The internal consistency was good for all dimensions, as the Cronbach's alpha coefficient ranged from 0.77 to 0.85 depending on dimensions. The Spearman correlation coefficient between each MSAS dimension and the SymptoMScreen score varied between 0.0.32 and 0.578 (see supplementary material 7).

3.3. Construct validity

The construct validity of the final MSAS questionnaire was evaluated using an ANOVA to estimate the relation between this reduced questionnaire dimension scores and the disease severity classes assessed by the SymptoMScreen questionnaire (score <25, [25-48], and >48). Table 6 displays the association for each dimension.

The higher the score for a dimension, the higher was the burden, except for two dimensions [Your involvement in activities for yourself (sports, recreational activities, travel)/ Your participation in activities with others)], where lower scores were associated with higher burden.

Table 3
Main characteristics of patients of the total and analyzable populations – Field test.

	Total population (*N* = 708)	Analyzable population (*N* = 653)
Female patient – n (%)	586 (83.7)	544 (83.6)
Age in 2022 (years) - mean (SD)	46.0 (11.7)	46.0 (11.6)
Duration of multiple sclerosis (years) – median (IQR)	8.0 (3.0–16.0)	8.0 (3.0–16.0)
Quasi constant mobility assistance required – n (%)	143 (20.5)	134 (20.6)
Other comorbidity(ies) impacting daily activities – n (%)	115 (16.5)	104 (16.0)
SymptoMScreen (range: 0–72)		
Median score (IQR)	25 (16–35)	25 (16–36)
Score ≥30 – n (%)	251 (35.5)	240 (36.8)

IQR, interquartile range; SD, standard deviation

Associations were strong ($p < 0.05$) for 6 out of the 10 dimensions. Increased disease symptoms (greater SymptoMScreen score) were associated with less participation of patients to personal, professional activities or medical decisions regarding their disease. Level of support from others (at home or at work) were not associated with disease symptoms. These results confirmed the construct validity of the MSAS questionnaire.

The multitrait analysis confirmed that correlation of each item is higher within their dimension than with the other dimensions (see supplementary material 5).

A first and non-validated English translation of the MSAS questionnaire is provided for information in supplementary material 9.

4. Discussion

Nowadays, MS management is mainly driven by the monitoring of clinical and radiological outcomes (relapses and imaging lesions) (Lublin et al., 2014), leading to commonly used functional scales as the

Table 2
Preliminary and final MSAS questionnaires.

PRELIMINARY QUESTIONNAIRE		FINAL MSAS QUESTIONNAIRE	
Dimensions (N=13)	***Questions (N=131)***	***Dimensions (N=10)***	***Questions (N=36)***
Seven dimensions concerning all the patients		**Five dimensions concerning all the patients**	
Relations with your healthcare teams	*9*	To be taken into account by your healthcare team	*3*
Recreational and sport activities	*8*	Your involvement in activities for yourself (sports, recreational activities, travel)	*3*
Relationships and activities with friends	*12*	The support from your friends	*4*
Relationships in public	*12*	The control on the image you conveyed to others	*4*
Life at home	*5*	Your participation in activities with others	*5*
Life in general	*6*		
Familial relationships and activities	*11*		
Six dimensions concerning specific patients		**Five dimensions concerning specific patients**	
Relationships and activities with children	*11*		
Relationships and activities with partner	*12*	The support from your partner	*3*
Relationships and activities with grandchildren	*9*	Your role as grandparent	*3*
Professional relationships and activities	*25*	To be taken into account at work	*4*
		Your professional activities	*4*
Student relations and activities	*4*		
Relations and activities related to associations and extra-professional life	*7*	Your involvement in a club or associative group	*3*

MSAS, Multiple Sclerosis Autonomy Scale

Table 4
Detailed patient characteristics - Analyzable population – Field test.

	SymptoMScreen score <30 (*N* = 413)	SymptoMScreen score ≥30 (*N* = 240)	Analyzable population (*N* = 653)
Female patient – n (%)	348 (84.5)	196 (82.0)	544 (83.6)
Inter-group test	*0.4147*		
Age in 2022 (years)			
Mean (SD)	44.3 (11.1)	48.8 (11.8)	46.0 (11.6)
Classes – n (%)			
<30	36 (8.7)	10 (4.2)	46 (7.1)
[30-40[	115 (27.9)	45 (18.8)	160 (24.6)
[40-50[	131 (31.8)	67 (28.0)	198 (30.4)
[50-60[	93 (22.6)	74 (31.0)	167 (25.7)
≥60	37 (9.0)	43 (18.0)	80 (12.3)
Inter-group test	*<0.0001*		
Age at MS diagnosis (years)			
Mean (SD)	34.1 (10.1)	36.0 (11.1)	34.8 (10.5)
Inter-group test	*0.0198*		
Duration of MS (years)			
Median (IQR)	8.0 (3.0-15.0)	10.0 (4.0-19.0)	8.0 (3.0-16.0)
Classes – n (%)			
<5	140 (34.1)	65 (27.2)	205 (31.6)
[5-15]	175 (42.7)	97 (40.6)	272 (41.9)
>15	95 (23.2)	77 (32.2)	172 (26.5)
Inter-group test	*0.0283*		
Quasi-constant mobility assistance required – n (%)	48 (11.7)	86 (36.0)	134 (20.6)
Inter-group test	*<0.0001*		
Other comorbidity (ies) impacting daily activities – n (%)	43 (10.5)	61 (25.5)	104 (16.0)
Inter-group test	*<0.0001*		
Significant event impacting MS over the past 4 weeks – n (%)	87 (21.1)	96 (40.3)	183 (28.2)
Inter-group test	*<0.0001*		
SymptoMScreen (range: 0–72)			
Median score (IQR)	19 (14–24)	39 (34–44)	25 (16–36)
Inter-group test	*<0.0001*		

IQR, interquartile range; MS, multiple sclerosis; SD, standard deviation
% are based on non-missing data; F tests from ANOVA were used for inter-group tests.

Table 5
Patients concerned by each specific dimension of the preliminary questionnaire - Analyzable population – Field test.

Condition related to a specific dimension	Analyzable population (*N* = 653)
To live with a partner	500 (76.7 %)
To be parent	461 (70.7 %)
To be grandparent	97 (14.9 %)
To be student	11 (1.7 %)
To work	373 (57.2 %)
To be involved in a club or associative group	224 (34.5 %)

As only 11 patients (1.7 %) were concerned by the specific dimension related to student relations and activities, this dimension (with its 4 related questions) was not further analyzed. The other 12 dimensions were considered important by patients as between 55 % and 95 % of them gave a score of at least 8 using a 10-point rating scale for ranking (Supplementary material 8). Among the seven dimensions concerning all the patients, the two most important for them were "Relations with healthcare teams" and "Life at home" (score of importance ≥8 for 88.9 % and 94.5 % of patients, respectively). Regarding the five dimensions concerning specific patients (excluding student relations and activities), the two most important for them were "Relations and activities with children" and "Relations and activities with grandchildren" (score of importance ≥8 for 94.8 % and 91.8 % of concerned patients, respectively).

Expanded Disability Status Score (EDSS) to assess the MS evolution. However, the complexity of the disease, the difficulty in choosing the most adapted treatment and the wide range of potential symptoms call for a comprehensive approach to the patient. The autonomy of PwMS takes this complexity into account by covering a broader spectrum than their mere functional abilities. Consequently, we developed a new PROM with the aim to extend patient management to fully acknowledge the disease burden on ADL conducting to some losses of autonomy. Our research is in line with the increasing importance of real-life patient data as recommended by French, European, and US Health Authorities to measure patient perceptions (Food and Drug; European Medicines Agency. Doc. Ref. EMEA/CHMP/EWP/139391/2004, 2005; Autorité de santé, 2021).

To our knowledge, no researches with a similar objective were performed even if other scales were previously developed to assess the MS impact on patient life. In particular, the MSIS-29, a PROM validated after a similar step-by-step process, measures the physical and psychological MS burden from the patients' perspective (Hobart et al., 2001). The personal autonomy of patients with MS was also previously explored, as it is a key component in the successful patient-physician relationship and adherence to medical decisions (Heesen et al., 2013; Padureanu et al., 2020).

To develop the new MSAS questionnaire, we followed a rigorous scientific approach based on the experience of PwMS themselves: they were asked to report the importance of the impact of the MS on their roles, and to rank them.

The first qualitative step was based on an innovative sociological approach in this disease, and led to define the autonomy as perceived by PwMS (to be able to carry out the roles the patient thinks the most important whether or not he/she receives assistance). The preliminary questionnaire (131 items grouped into 13 social dimensions) generated thereafter was validated in four patient focus groups and then completed by a large population of PwMS using a secured website platform. The internal and construct validities of the reduced final questionnaire (36 questions grouped into 10 dimensions) were confirmed.

Our research has potential limitations. In particular, the quantitative step was conducted without any data medically validated by a physician since only patients were asked to participate. In addition, students, who are few to suffer from MS in real life, seem to be less concerned by our scale focused on autonomy (specific questions associated to the students' life were excluded from our analysis since students were too few). Finally, patients without internet access could not complete the online preliminary questionnaire. However, to favor the representativeness of our studied population, all efforts were made to inform PwMS on the implementation of the research: the link to the online questionnaire was shared with potential participants by email, newsletters, through posts on different social networks and articles on patient association's websites, to mobilize their community. It was also shared by healthcare professionals using flyers and posters. In addition, a community of 200 PwMS, already registered to the MoiPatient service, the distribution platform for the questionnaire, also received an invitation to participate using the link. All these efforts led to the diversity of our analyzed population in terms of general characteristics of PwMS as they were similar to those reported in last data from 86,582 medical files analyzed on December 2022 by the *Observatoire français de la sclérose en plaques* (OFSEP cohort) (OFSEP, 2023): female patients (84 % using the MSAS *versus* 81 % in OFSEP); patient age at MS diagnosis (34.8 ± 10.5 *versus* 32.7 ± 10.9 years). That being said, there was no attempt in the quantitative step of the study to reach representativeness of the French MS population as this is acceptable under the assumption that psychometric validation relies mainly on internal validity. In addition, the number of analyzed PwMS was large and consistent with the planned sample size, and missing data from the patient online questionnaire were limited.

Table 6
Construct validity - Association between SymptoMScreen and MSAS dimensions.

Mean (SD) dimension score (min:1 / max:6)	SymptoMScreen Score [0-24] ($N = 314$)	SymptoMScreen Score [25-48] ($N = 310$)	SymptoMScreen Score >48 ($N = 29$)	P-value
Five dimensions concerning all the patients				
To be taken into account by your healthcare professional teams	4.22 (1.33)	3.82 (1.36)	4.38 (1.26)	0.0004
Your involvement in activities for yourself (sports, recreational activities, travel)	3.68 (1.65)	3.02 (1.61)	2.53 (1.51)	<0.0001
Your participation in activities with others	4.42 (0.97)	3.4 (0.96)	2.61 (0.98)	<0.0001
The support from your friends	3.45 (1.07)	3.58 (1.1)	3.66 (1.3)	0.261
The control on the image you conveyed to others	2.14 (1.05)	2.91 (1.24)	2.86 (1.28)	<0.0001
Five dimensions concerning specific patients				
The support from 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
Your professional activities	2.84 (1.37)	3.83 (1.39)	4.53 (1.52)	<0.0001
Your involvement in a club or associative group	4.25 (1.45)	3.99 (1.49)	4.14 (1.11)	0.408

5. Conclusions

Our research allowed to build a new patient questionnaire covering all the aspects of the autonomy of patients suffering from MS, newly defined to cover a broader spectrum than patient functional abilities: the Multiple Sclerosis Autonomy Scale (MSAS). The next step of this research, aiming to validate MSAS among 200 PwMS, will be soon implemented in a confirmatory study to provide an easy-to-use tool in the context of the relations between healthcare professionals and PwMS, and to be used in future clinical trials for treatment assessment.

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Data availability

The datasets supporting the conclusions of this article are available from the corresponding author upon reasonable request.

CRediT authorship contribution statement

Cécile Donzé: Writing – review & editing, Conceptualization, Methodology, Supervision, Visualization. **Claude Mekies:** Writing – review & editing, Conceptualization, Methodology, Supervision, Visualization. **Géraud Paillot:** Writing – review & editing, Conceptualization, Methodology, Supervision, Visualization. **Patrick Vermersch:** Writing – review & editing, Conceptualization, Methodology, Supervision, Visualization. **Guillaume Montagu:** Writing – review & editing, Conceptualization, Methodology. **Lucie Brechenmacher:** Writing – review & editing, Conceptualization, Methodology, Project administration, Supervision, Visualization. **Alexandre Civet:** Writing – review & editing, Conceptualization, Data curation, Formal analysis, Methodology, Validation. **David Pau:** Writing – review & editing, Conceptualization, Data curation, Formal analysis, Methodology, Validation. **Catherine Mouzawak:** Writing – review & editing, Conceptualization, Methodology, Supervision, Visualization. **Mikael Cohen:** Writing – review & editing, Conceptualization, Methodology, Supervision, Visualization.

Declaration of competing interest

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Supplementary materials

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