

# Psychometric assessment of the Persian version of the patient determined disease steps scale in patients with multiple sclerosis and neuromyelitis optica spectrum disorder

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## Keywords

Multiple Sclerosis; Persian; Reliability; Validity

## Abstract

**Background:** The purpose of this study was to evaluate the validity and reliability of the Persian version of Patient Determined Disease Steps (PDDS) in both patients with multiple sclerosis (MS) and neuromyelitis optica spectrum disorder (NMOSD).

**Methods:** One hundred and forty-five patients were enrolled between May and September 2020 by consecutive sampling. Participants were asked to complete timed 25-foot walk (T25FW), 12-item Multiple Sclerosis Walking Scale (MSWS-12), and Multiple Sclerosis Quality of Life-54 (MSQOL-54). Patients also completed Timed Up and Go (TUG) and six-minute walk

(6MW) tests. Construct validity was assessed by calculating correlation between PDDS and ambulatory and demographic items. The intra-class correlation coefficient (ICC) was used to evaluate reliability.

**Results:** One hundred and eleven patients with MS and 34 with NMOSD with disease duration of  $7.6 \pm 5.8$  years were enrolled. Twenty-seven percent were men and mean Expanded Disability Status Scale (EDSS) was  $1.8 \pm 1.8$ .

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There was a significant positive correlation between EDSS and PDSS ( $\rho = 0.64$ ,  $P < 0.001$ ) which was evident in MS subgroups and NMOSD [secondary progressive MS (SPMS):  $\rho = 0.64$ ,  $P < 0.001$ ; relapsing-remitting MS (RRMS):  $\rho = 0.47$ ,  $P < 0.001$ ; NMOSD:  $\rho = 0.52$ ,  $P = 0.001$ ]. PDDS had also significant positive correlation with TUG, T25FW, and MSWS-12. PDDS had also significant negative correlation with 6MW test. PDDS had weak correlation with demographic variables. The ICC was calculated as 0.99 for PDDS.

**Conclusion:** The Persian version of PDDS provides valid and reliable instrument to assess MS/NMOSD-related disability.

### Introduction

Multiple sclerosis (MS) is an autoimmune disease of the central nervous system (CNS)<sup>1,2</sup> manifesting with neurological symptoms such as walking impairment, affecting the quality of life.<sup>3</sup> Up to now, the disease progression in patients with MS is evaluated by Kurtzke Expanded Disability Status Scale (EDSS).<sup>4</sup> The application of EDSS needs careful examination by a neurologist and is time-consuming.<sup>5</sup>

Patient Determined Disease Steps (PDDS) scale was developed by the North American Research Committee on Multiple Sclerosis (NARCOMS) which could be reported by the patient in a short time and is considered as a surrogate of the EDSS.<sup>6</sup>

PDDS does not need clinical evaluation and could be considered as a patient-reported outcome (PRO) of disability in MS cases.<sup>7</sup> It consists of 9 ordinal rating ranging from 0 (normal) to 8 (bedridden).<sup>8</sup>

Literature shows that there is a strong correlation between PDDS and EDSS as well as other PROs such as the 12-item Multiple Sclerosis Walking Scale (MSWS-12) score.<sup>9-11</sup>

PDDS has been translated and validated in some countries but it is not assessed in Iran. Therefore, we designed this study to evaluate validity and reliability of the Persian version of PDDS in both patients with MS and patients with neuromyelitis optica spectrum disorder (NMOSD).

### Materials and Methods

This cross-sectional study was conducted in Kashani Hospital (affiliated hospital of Tehran University of Medical Sciences, Tehran, Iran) between May and September 2020 by consecutive sampling.

**Ethical consideration:** All patients were asked to fill informed consent forms after clear description of the goals of the study.

Inclusion criteria were confirmed diagnosis of MS based on 2017 McDonald criteria, definite neuromyelitis optica (NMO) diagnosis, and age more than 18. Exclusion criterion was relapse of the disease during the last month.

**Translation and adaptation:** PDDS is a newly developed PRO which is scored between 0-8 and is indicative of disability.

By the forward-backward translation method, a bilingual medical researcher translated the questionnaire into Persian and then another bilingual researcher translated the Persian version into English. The two versions were compared by a neurologist.

### Validity assessment

**Content validity:** Five neurologists checked the content validity. They assessed if the questions were relevant and necessary.

**Construct validity:** To assess construct validity, we used different measures such as:

**A. Timed 25-foot walk (T25FW):** T25FW is a measure of walking speed. The participant is asked to walk (with/without the device) in a safe and quick way in a hallway clear of obstacles. The shorter mean time (after two trials) was recorded as faster walking speed.<sup>12</sup> The valid Persian version was administered.<sup>13</sup>

**B. Timed Up and Go (TUG):** This test includes standing up, walking, turning, and sitting down, assessing walking mobility.<sup>14</sup> We asked the patient to seat on a chair, then stand up with arms crossed over the chest, walk around an object which was placed 10 feet in front of the chair, and finally return to the chair. The participants had to complete two trials and mean time (s) to complete the TUG was recorded. The shorter the time, the better the walking mobility.<sup>15</sup>

**C. Six-minute walk (6MW):** This test administers a rectangular and carpeted course with four hallways that each exceeds 50 m in length. The participants would walk in a clockwise pattern around the entire course during the 6MW. Patients should walk as far as they can during the six minutes. The distance was measured as meters using a measuring wheel (Stanley MW50, New Britain, CT, USA), while longer distances reflected better walking endurance.<sup>16</sup>

**D. MSWS-12:** This questionnaire includes 12 items evaluating the impact of MS on walking.<sup>17</sup> Each question is scored in a Likert scale ranging between 1 (not at all) and 5 (extremely). The total score is obtained by summing of all scores, subtracting the minimum possible score (12), and then dividing by the maximal score (48). Then final

score will be obtained by multiplying the result by 100. Therefore, final score ranges between 0-100, and lower the score, better walking ability.<sup>13</sup>

**E. Multiple Sclerosis Quality of Life-54 (MSQOL-54):** MSQOL-54 is a structured, self-report questionnaire containing 14 subscales (physical function, role limitations-physical, role limitations-emotional, pain, emotional well-being, energy, health perceptions, social function, cognitive function, health distress, overall quality of life, sexual function, satisfaction with sexual function, and change in health).<sup>18</sup>

**Reliability:** To assess reliability, twenty patients filled the questionnaire two weeks later.

Data regarding age, sex, education, marital status, disease duration, and EDSS were recorded for all.

All data were analyzed using SPSS software (version 23, IBM Corporation, Armonk, NY, USA). Data were presented as mean ± standard deviation (SD) for continuous or frequencies for categorical variables. The intra-class correlation coefficient (ICC) was measured for repeatability evaluation, and ICC coefficient over 0.70 was considered acceptable. The correlation coefficient between these items and PDDS was considered as convergent validity (as a subtype of construct validity). Cronbach's alpha was calculated for internal validity assessment.

## Results

**A. Sample characteristics:** During the study period, 145 individuals participated. One hundred and eleven had MS and 34 had NMOSD. Basic characteristics are summarized in table 1.

**Table 1.** Basic characteristics of the patients

Variable	Value
Type of the disease [n (%)]	
RRMS	73 (50.3)
SPMS	38 (26.2)
NMOSD	34 (23.4)
Sex [n (%)]	
Men	39 (26.9)
Women	106 (73.1)
Marital status [n (%)]	
Single	31 (21.4)
Married	103 (71.0)
Divorced	11 (7.6)
Education (year) (mean ± SD)	14.5 ± 4.2
Duration of the disease (year) (mean ± SD)	7.6 ± 5.8
EDSS (mean ± SD)	1.8 ± 1.8

RRMS: Relapsing-remitting multiple sclerosis; SPMS: Secondary progressive multiple sclerosis; NMOSD: Neuromyelitis optica spectrum disorder; EDSS: Expanded Disability Status Scale; SD: Standard deviation

The most PDDS score of participants was 0 (Table 2).

**Table 2.** Mean scores of tests in included participants

Tests	Results
TUG	12.0 ± 9.0
Six-minute walk	333.2 ± 360.0
T25FW	15.6 ± 6.3
MSWS-12	28.5 ± 30.7
PDDS	
0	61 (42.1)
1	29 (20.0)
2	12 (8.3)
3	27 (16.8)
4	10 (6.9)
5	6 (4.1)
MSQOL-54	
Physical function	67.1 ± 33.8
Role limitations-physical	63.4 ± 41.3
Role limitations-emotional	56.4 ± 42.3
Bodily pain	69.7 ± 23.9
Emotional wellbeing	60.1 ± 21.0
Energy	54.4 ± 20.0
Health perceptions	60.7 ± 22.0
Social function	68.7 ± 23.7
Cognitive function	76.5 ± 74.4
Health distress	69.0 ± 28.1
Sexual function	72.2 ± 31.1
Change in health	52.4 ± 27.2
Satisfaction with sexual function	63.2 ± 29.9
Overall quality of life	37.3 ± 16.2

Data are presented as mean ± standard deviation (SD) or number and percentage

TUG: Timed Up and Go; T25FW: Timed 25-foot walk; MSWS-12: 12-item Multiple Sclerosis Walking Scale; PDDS: Patient Determined Disease Steps; MSQOL-54: Multiple Sclerosis Quality of Life-54

**B. Validity:** Cronbach's alpha was calculated as 0.99 which indicates high internal validity.

**Construct convergent validity:** There was a significant positive correlation between EDSS and PDDS ( $\rho = 0.64$ ,  $P < 0.001$ ) which was evident in MS subgroups and NMOSD [secondary progressive MS (SPMS):  $\rho = 0.64$ ,  $P < 0.001$ ; relapsing-remitting MS (RRMS):  $\rho = 0.47$ ,  $P < 0.001$ ; NMOSD:  $\rho = 0.52$ ,  $P = 0.001$ ].

PDDS had also a significant positive correlation with TUG, T25FW, and MSWS-12 and a significant negative correlation with 6MW test. It had a weak correlation with demographic variables (Table 3).

The scatter plot shows correlation between PDDS and EDSS (Figure 1). The ICC was calculated as 0.99 for PDDS.

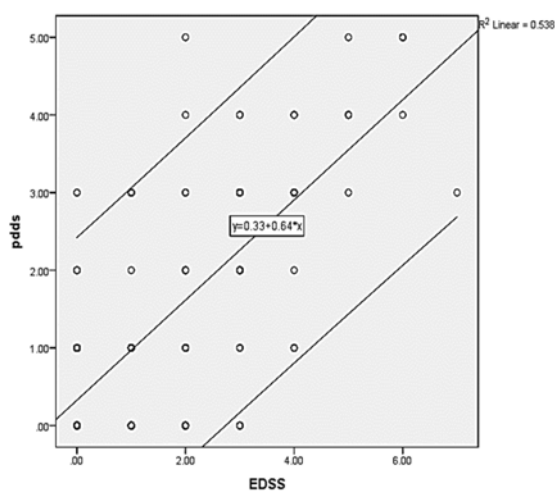
## Discussion

The goal of this study was to assess the validity and reliability of Persian version of PDDS in patients with MS/NMOSD.

**Table 3.** Correlation coefficients between Patient Determined Disease Steps (PDDS), Expanded Disability Status Scale (EDSS), and other variables

Variable	PDDS		EDSS	
	r	P	r	P
TUG	0.60	< 0.001	0.60	< 0.001
Six-minute walk	-0.60	< 0.001	-0.61	< 0.001
T25FW	0.60	< 0.001	0.62	< 0.001
MSWS-12	0.71	< 0.001	0.67	< 0.001
MSQOL-54	-0.20	0.010	-0.19	0.010
Physical health	-0.66	< 0.001	-0.61	< 0.001
Role limitations-physical	-0.65	< 0.001	-0.49	< 0.001
Pain	-0.43	< 0.001	-0.31	< 0.001
Disease duration	0.20	0.001	0.33	< 0.001
Age	0.36	< 0.001	0.52	< 0.001
Education	-0.34	< 0.001	-0.39	< 0.001

TUG: Timed Up and Go; T25FW: Timed 25-foot walk; MSWS-12: 12-item Multiple Sclerosis Walking Scale; PDDS: Patient Determined Disease Steps; MSQOL-54: Multiple Sclerosis Quality of Life-54; EDSS: Expanded Disability Status Scale

**Figure 1.** Scatter plot of Expanded Disability Status Scale (EDSS) and Patient Determined Disease Steps (PDDS)

The results showed that PDDS had a strong correlation with EDSS which shows convergent validity (a subtype of construct validity). The correlation was stronger in SPMS cases than RRMS or NMOSD ones. This finding could show the validity of PDDS as a PRO which is easy to use, accessible, and cost-effectiveness.

In previous studies that Turkish, English, and Italian versions were assessed, there was a significant positive correlation between EDSS and PDDS,<sup>5,19,20</sup> indicating that PDDS could be a good alternative for EDSS for assessing disability in both MS and NMOSD cases.

EDSS is an objective assessment of disability in MS/NMOSD cases, while it is time-consuming, needing patient's collaboration and careful neurological examination. It is difficult, especially

for more disabled cases.

We also found that PDDS was strongly correlated with T25FW, TUG, and MSWS-12 which are ambulatory assessments and could show the level of disability. This finding confirms previous findings.<sup>5,19</sup>

Originally, PDDS was developed based on ambulation and motor functioning which are the focus of disability assessment in patients with MS/NMOSD.<sup>21</sup> Therefore, strong correlation between PDDS and ambulatory tests was expected.

We also found that both PDDS and EDSS had a significant negative correlation with physical health and role limitations-physical aspects of MSQOL-54. The correlation was stronger for PDDS.

To assess divergent validity, the correlation between PDDS, age, education, and disease duration was evaluated and results demonstrated a weak correlation which was similar for EDSS; they are compatible with findings of previous studies.<sup>5,11,20</sup>

The test-retest reliability showed that the Persian version of the PDDS had a high reliability (ICC = 0.99). The Turkish and Italian versions of the PDDS had high reliability too (ICC = 0.99, ICC = 0.95, respectively).<sup>19,20</sup>

EDSS is a popular and widely-used instrument for a disability evaluation in MS/NMOSD cases which was developed by Kurtzke.<sup>4</sup> It is a clinician-administered instrument, evaluating the function of CNS, rating from 0 (normal neurological status) to 10 (death due to MS) 0.5 increment intervals (when reaching EDSS 1).<sup>22</sup> It is one of the endpoints of randomized controlled trials (RCTs). The higher the score, the higher the level of disability. To record EDSS, careful examination should be done

and patient collaboration plays an important role. On the other hand, physician should pay attention and spend time recording EDSS.

PDDS was developed by NARCOMS as a PRO of disability as a surrogate of EDSS, ranging between 0 (normal) and 8 (bedridden).<sup>6,7</sup> It is simple and easy to use and could be answered during a short time. Thus, it has the potential to be used in clinical evaluation.

Our study had some strengths. First, we included both MS and NMO/MS cases. Second, individuals with RRMS and SPMS were recruited too.

We also had some limitations. First, we did not include highly disabled cases (higher EDSS) which could distort the spectrum of the patients. Second,

we only did a cross-sectional study which had no follow-up to evaluate PDDS changes during the time alongside the changes of EDSS.

### Conclusion

The Persian version of PDDS provides a valid and reliable instrument to assess MS/NMO/MS-related disability.

### Conflict of Interests

The authors declare no conflict of interest in this study.

### Acknowledgments

None.

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