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Validity and Reliability of the Turkish Version of the Self-Reported Disability Status Scale in Persons with Multiple Sclerosis

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ABSTRACT

Objective: The aim of this study was designed to investigate the validity, reliability, and cultural adaptation of the Turkish version of the self-reported disability status scale (SRDSS). **Materials and Methods:** This study was designed as prospective, methodological, and cross-sectional. Turkish translation and cross-cultural adaptation of SRDSS was conducted. SRDSS scores were compared with Expanded Disability Status Scale and Patient Determined Disease Steps to test the concurrent validity. The validity and test-retest reliability of the Turkish SRDSS were investigated in 128 persons with MS. **Results:** A very strong correlation was found between SRDSS and Expanded Disability Status Scale (r=-0.920, p=0.000) and Patient Determined Disease Steps (r=0.857, p=0.000). The mean of the first test of SRDSS was 1.29±0.59, and the mean of the retest test was 1.30±0.61. A very high correlation was found between test and retest (p<0.001, r=0.967). Bland-Altman analysis showed that SRDSS was reproducible with upper and lower limits of agreement of 0.2929 and -0.3089, respectively (bias=-0.008; p=0.566). Cronbach's alpha coefficient was found to be 0.983 (excellent reliability). For inter-rater agreement, the ICC values in the individual test were 0.967 (954 CI; 0.954–0.977). **Conclusion:** This study showed that the Turkish version of SDRSS is a valid and reliable measurement tool. In cases where Expanded Disability Status Scale cannot be applied, the Turkish version of SRDSS can be used as an alternative assessment method.
Keywords: Multiple Sclerosis, Self-report, Validity, Reliability, Scale.

Multipl Sklerozlu Bireylerde Öz Bildirimli Engellilik Durumu Ölçeğinin Türkçe Versiyonunun Geçerliliği ve Güvenilirliği

ÖZ

Amaç: Bu çalışmanın amacı, Özbildirimli Engellilik Durumu Ölçeği'nin (SRDSS) Türkçe versiyonunun geçerliliğini, güvenilirliğini ve kültürel uyarlamasını araştırmaktır. **Gereç ve Yöntem:** Bu çalışma prospektif, metodolojik ve kesitsel olarak tasarlandı. SRDSS'nin Türkçe çevirisi ve kültürler arası uyarlaması yapıldı. Eşzamanlı geçerliliği test etmek için SRDSS puanları Genişletilmiş Engellilik Durum Ölçeği ve Hasta Tarafından Belirlenmiş Hastalık Adımları ile karşılaştırıldı. Türkçe SRDSS'nin geçerlik ve test-tekrar test güvenirliği MS'li 128 kişide incelendi. **Bulgular:** SRDSS ile Genişletilmiş Engellilik Durum Ölçeği (r=-0.920, p=0.000) ve Hasta Tarafından Belirlenmiş Hastalık Adımları (r=0.857, p=0.000) arasında çok güçlü bir korelasyon bulundu. SRDSS'nin ilk test ortalaması 1.29±0.59, tekrar test ortalaması 1.30±0.61 olarak tespit edildi. Test ile retest arasında çok yüksek bir korelasyon bulundu (p<0.001, r=0.967). Bland-Altman analizinde sırasıyla 0.2929 ve -0.3089 üst ve alt uyuşma sınırlarıyla SRDSS'nin tekrarlanabilir olduğunu gösterdi (bias= -0.008; p = 0.566). Cronbach's alpha katsayısı 0,983 (mükemmel güvenirlik) olarak bulundu. Değerlendiriciler arası uyum için, bireysel testteki ICC değerleri 0.967'dir (%95 CI; 0.954–0.977). **Sonuç:** Bu çalışma, SDRSS'nin Türkçe versiyonunun geçerli ve güvenilir bir ölçme aracı olduğunu göstermiştir. Genişletilmiş Engellilik Durum Ölçeği'nin uygulanamadığı durumlarda, alternatif bir değerlendirme yöntemi olarak SRDSS'nin Türkçe versiyonu kullanılabilir.
Anahtar Kelimeler: Multipl Skleroz, Öz Bildirim, Geçerlik, Güvenirlik, Ölçek.

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INTRODUCTION

Multiple sclerosis (MS) is a chronic inflammatory demyelinating and neurodegenerative disease of the central nervous system that affects health-related quality of life with increasing disability (physical, cognitive, and mental) over time (Ercan et al., 2021; Reich et al., 2018). One of the most important causes of disability in persons with MS (PwMS) is gait disturbance (Coca-Tapia et al., 2021). The Expanded Disability Status Scale (EDSS), which has been the most widely used method for measuring disability in the MS field for many years, is largely based on the patient's ability to walk (Kurtzke, 1983). Despite recognized shortcomings (focusing on gait disturbances rather than pain and fatigue, cognition, and emotional disturbances), the EDSS is still considered the gold standard for measuring disability (Zurawski et al., 2019). EDSS requires a complete neurological assessment by a certified EDSS assessor in a clinical-based setting (Kurtzke, 1983; Zurawski et al., 2019). Therefore, EDSS is not always suitable for work by non-certified healthcare professionals or with large populations on a community basis. In addition, because the EDSS is a clinician-administered assessment tool, the disability level determined in MS does not reflect the patient's perspective. Therefore, EDSS means little to PwMS. As a result, it was found that most of the PwMS lack information about their EDSS scores (Bovis et al., 2018; Puhan et al., 2018; Steinemann et al., 2018). So much so that in the study investigating the quality of life of PwMS living in Europe, the possibility of incorrectly estimating the EDSS of some patients was stated as a limitation. However, at the time of data collection in the same study, it was stated that the Self-Reported Disability Status Scale (SRDSS) as a proxy measure to predict EDSS was not yet available, but such a measure could be useful for self-assessment of disability in an online survey setting (Visser et al., 2021). The preference of SRDSS in patient-reported studies in the current literature also shows the necessity and need of the scale (Fortunato et al., 2021; Rodgers et al., 2021a; Rodgers et al., 2021b).

For all these reasons, there is a need for concise, reliable and robust tools for self-assessments of disability that offer comparability with the EDSS. Because it is very difficult to know the EDSS value in self-reported studies involving the MS patient population or in online survey studies. For these reasons, up-to-date, valid and reliable scales are needed to estimate the EDSS value in patients who are inaccessible to EDSS certified healthcare professionals. It has been detected that the SRDSS developed for this purpose can predict EDSS categories based on self-reported information (Kaufmann et al., 2020). SRDSS can help contextualize results from observational studies by incorporating findings into a rough estimate of neurological status. Nonetheless, due to its focus on mobility, SRDSS also lacks sensitivity to fine-grained differences in the transitions of categories and therefore is prone to certain misclassifications (Kaufmann et al., 2020). The absence of a Turkish version of the SRDSS limits its potential use in Turkey and in countries with Turkish-speaking populations. The Turkish version of the SRDSS is thought to be useful as a patient-reported outcome measure that does not require any training, is easily accessible, and can be easily applied as an alternative to EDSS. The aim of this study was designed to investigate the validity, reliability, and cultural adaptation of the Turkish version of the SRDSS.

MATERIALS AND METHODS

Study design

This study was designed as prospective, methodological, and cross-sectional. The first evaluations of the participants were carried out in the hospital. The retest evaluations of the participants were performed in their own living spaces (home, patient care center, etc.) 3 - 5 days later. To test the concurrent validity of the SRDSS, it was compared with the EDSS and the Patient Determined Disease Steps (PDDS) scale. For this purpose, Turkish versions of EDSS and PDSS were used. It was assumed that the clinical conditions of the participants did not change during the study. No new treatment was given during this period to minimize the risk of short-term clinical changes in the participants.

Participants

Individuals with a definite diagnosis of MS according to the McDonald criteria and ≥18 years were included in this study. We excluded those who had an exacerbation in the past 90 days, a neurological disease other than MS (for example, Parkinson's, Stroke, vertigo, etc.), or with one or more concomitant comorbidities.

Body mass indexes, last attack dates, EDSS values, type and duration of MS, and sociodemographic data of the participants were recorded.

Translation and cross-cultural adaptation

Permission to use the original SRDSS was obtained from Dr. Marco Kaufmann for the Turkish validity study. The cultural adaptation procedure of SRDSS was performed in accordance with the principles described in the literature (Arafat et al., 2016).

First, the SRDSS form was translated into Turkish by two interpreters who were Turkish nationals with a high level of proficiency in English. Both the interpreters and authors compared the translations and formed a Turkish version that best represented the original form. Afterward, the translation was piloted with two elderly individuals to assess its linguistic intelligibility and appropriateness. The second meeting was performed to form a consensus on the necessary changes and it was decided that there was no need for cultural adaptation. Secondly, the Turkish form of SRDSS was back-translated into English by two native English interpreters who were blinded to the study. In the third step, the two back-translation forms were synthesized and compared with the original SRDSS form by the authors. Finally, the Turkish version, the back-translated form, and the original SRDSS form were compared by a multidisciplinary team including physiotherapists and neurologists, in order to detect the inconsistent parts within the text and to ensure semantic and conceptual equivalence. After a series of small alterations and corrections, a consensus was reached by the team and Dr. Dr. Marco Kaufmann Ultimately, the final Turkish version

of the SRDSS was obtained and a pilot study was performed with 10 PwMS.

Evaluations

SRDSS described in this study was created to represent mobility-centered descriptions of predefined EDSS categories (Kaufmann et al., 2020). In addition, PDSS, which was developed as an alternative to EDSS, is used as a patient-reported outcome measure to assess disability in PwMS (Kahraman et al., 2021). Therefore, EDSS and PDSS were used to determine the reliability and validity of SRDSS.

Self-Reported Disability Status Scale (SRDSS): SRDSS was created to represent predefined EDSS categories (Kaufmann et al., 2020; Wallin et al., 2019). The SRDSS was based on three self-reported questions that covered all values according to the EDSS. The first question was about the distance an individual with MS could walk on flat terrain (< 10 m, 10 to 500 m, ≥ 500 m). The second question is whether the PwMS uses any walking aid (cane or wheelchair). Finally, the third question was about whether the PwMS uses a wheelchair or not. Following the predefined decision tree, the results according to the answers resulted in one of three values (SRDSS ≤ 3.5, 4 - 6.5,≥7) (Figure 1) (Kaufmann et al., 2020).

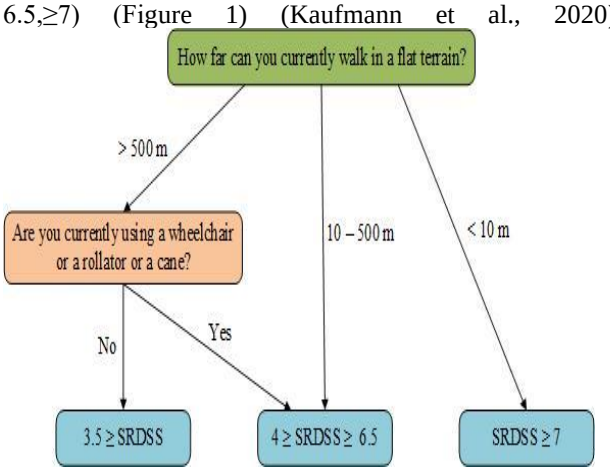

Figure 1. Simplified decision tree to build the self-reported disability status scale (SRDSS).

Extended Disability Status Scale: The level of neurological disability of individuals with MS was determined by the EDSS, a widely used scale. It was done by a certified neurologist with extensive experience in MS to determine the participants' EDSS scores. The EDSS is a 20-stage disease severity scale ranging from 0 (normal) to 10 (MS-related death) (Kurtzke, 1983).

Patient Determined Disease Steps Scale: The participant is asked to choose single items of the nine listed items (ranging from 0 to 8) that best describe their current walking ability status. These items are: "(0) normal"; "(1) mild disability"; "(2) moderate disability"; "(3) gait disability"; "(4) early cane"; "(5) late cane"; "(6) bilateral support"; "(7) wheelchair/scooter"; and "(8) bedridden" (Kahraman et al., 2021)

Statistical analysis

Data analysis was conducted using the SPSS 25.0 (SPSS Inc., Chicago, Illinois, USA) program. Continuous data were expressed as mean ± standard deviation (SD) and categorical variables were expressed as frequencies (f) and percentages (%). Kolmogorov-Smirnov test was used to check the normality of the distribution of variables. A wide range of recommendations regarding optimal sample size for factor analysis exists in the literature. We used a sample size approach that is at least 5-10 times larger than the number of scale items, which is one of the most recommended and supported recommendations (Everitt, 1975; Gözüm S, 2003). According to this approach, there should be at least between 5 to 10 participants for each item in the instrument. Our study was carried out with 128 participants for a total of 12 items of the SRDSS.The Cronbach's alpha reliability coefficient and test-retest reliability and intra-class correlation coefficient (ICC) were utilized for internal consistency in reliability analyses. The ICC coefficient was considered as values less than 0.5, between 0.5 and 0.75, between 0.75 and 0.9, and greater than 0.90 are indicative of poor, moderate, good, and excellent reliability, respectively (Koo & Li, 2016). Concurrent validity analysis was used to investigate the validity of the RDSS in MS individuals. For convergent validity, the relationship between SRDSS and EDSS, and PDSS was evaluated with the Pearson correlation test. Correlations were considered negligible if between 0 and 0.20, weak if 0.21–0.40, moderate if 0.41–0.60, strong if 0.61–0.80, and very strong if 0.81–1.00 (Prion & Haerling, 2014).

The absolute test-retest reliability was assessed calculating the coefficient of repeatability and investigating the Bland-Altman plot (Vaz, Falkmer, Passmore, Parsons, & Andreou, 2013). The 95% CI of the mean difference was used to determine systematic bias and it is interpreted that there was no systematic bias when the 95% CI includes zero (Bland & Altman, 1999). SRDSS was tested for normality using the Kolmogorov–Smirnov test, which determines whether the score value differs significantly from a normal distribution (Berger & Zhou, 2014).

Ethical considerations

PwMS were recruited from Fırat University Hospital, Department of Neurology. Ethical permission for the research was obtained on 26.03.2021 from Fırat University Ethics Committee (Decision number E-97132852-050.01.04-29959). All patients were informed about the study and gave their written consent before the study. This research was conducted in accordance with the principles of the Declaration of Helsinki.

RESULTS

The study population consisted of 128 individuals with MS, with a mean age of 34.28 years and 75.8% women. Most participants had relapsing-remitting MS (82.8%), while others had secondary-progressive MS (10.9%), primary-progressive MS (6.3%). The demographic and clinical characteristics data of the participants are presented in Table 1.

Table 1. The demographic and clinical characteristics of the participants.

	Mean±SD	min–max
Mean age (years)	34.78±11.03	19–61
BMI (kg/m^2)	25.66±5.37	16.60–43.2
Duration of disease (years)	7.43±5.69	1–26
SRDSS	1.29±0.59	1–3
EDSS	2.54±1.89	1–8
PDSS	2.09±1.88	0–7

SD=Standart deviation, BMI=Body mass index, SRDSS=Self-Reported Disability Status Scale, EDSS=Expanded Disability Status Scale, PDSS=Patient Determined Disease Steps.

Very strong correlation was revealed between the SRDSS and EDSS (r=-0.920, p=0.000, Figure 2), and PDSS (r=0.857, p=0.000) (Table 2). In addition, significant correlations were found between EDSS and PDSS (r=0.941, p=0.000) (Table 2).

The average of the first measurement of the SRDSS was calculated as 1.29±0.59, and the second measurement was calculated as 1.30±0.61. A very high correlation (p<0.001, r=0.967) was found between the first measurement of the test and the second measurement repeated 3 - 5 days later (Table 3).

Figure 3 represents the SRDSS test-retest reliability in Bland–Altman analysis performed in PwMS. The test showed that SRDSS is reproducible, with upper and lower limits of agreement of 0.2929 and −0.3089, respectively, on Bland–Altman analysis (bias = -0.008; p = 0.566). Cronbach's alpha coefficient was found to be 0.983 (excellent). For intra-rater agreement, the ICC values in the individual test were 0.967 (95% CI; 0.954–0.977, excellent agreement) (Table 3).

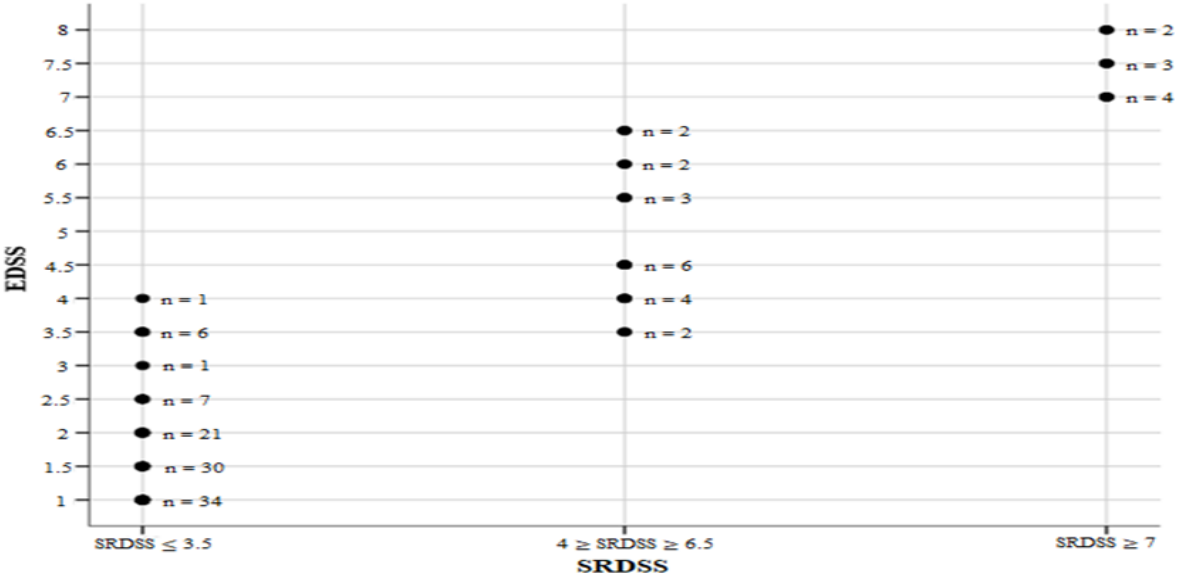

Figure 2. Correlation between number of SRDSS and EDSS. SRDSS: Self-Reported Disability Status Scale, EDSS: Expanded Disability Status Scale

Table 2. Correlation coefficients between SRDSS, EDSS and PDSS.

	SRDSS		EDSS		PDSS	
	r	**p**	**r**	**p**	**r**	**p**
SRDSS			0.920	0.000*	0.857	0.000*
EDSS	0.920	0.000*			0.941	0.000*
PDSS	0.857	0.000*	0.941	0.000*		

SRDSS= Self-Reported Disability Status Scale, EDSS= Expanded Disability Status Scale, PDSS= Patient Determined Disease Steps, r= Pearson's correlation coefficient, *p ≤ 0.001.

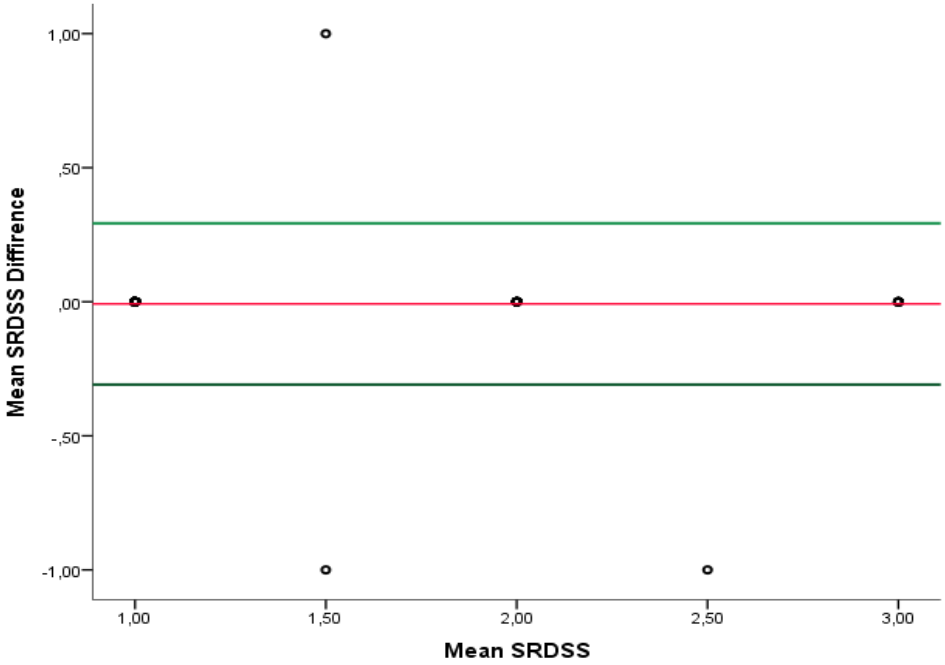

Figure 3. Bland–Altman plot of SRDSS for PwMS. *Central line represents the mean differences between T2–T1; the upper and lower lines represent the upper and lower 95% limits of agreement (mean differences ± 1.96 × SD of the differences). SRDSS: Self-Reported Disability Status Scale

Table 3. Test-retest reliability of the Turkish version SRDSS.

Test (Mean±SD)	Re-Test (Mean±SD)	Difference (Mean±SD)	ICC (95% CI)
1.29±0.59	1.30±0.61	0.009±0.012	0.967 (0.954–0.977)

SRDSS=Self-Reported Disability Status Scale, CI=Confidence interval, ICC=Intraclass correlation coefficient, SD=Standard deviation.

Kolmogorov–Smirnov test did not indicate a normal distribution of scores on SRDSS ($p < 0.05$). This shows that SRDSS has ceiling or floor effects.

DISCUSSION

The present study was founded that the Turkish version of the SRDSS is a reliable and valid questionnaire for PwMS. Where EDSS is not feasible (eg non-face-to-face assessment, lack of experienced staff for implementation, studies with large samples) SRDSS can be used as a reliable alternative method. To evaluate the effectiveness of practice, test outcome measures must be valid and reliable. With this study, the SRDSS was translated and cross-culturally adapted into Turkish for the first time.

Turkish version of the SRDSS showed that it has high validity and reliability.

As SRDSS was designed as a proxy for EDSS, we investigated the correlation between SRDSS and EDSS to assess criterion validity. In addition to this, we also investigated the correlation between the PDDS, which was developed as an alternative to the EDSS, and which was validity and reliability in Turkish, and SRDSS. A strong correlation was found between SRDSS and both EDSS and PDDS. Since SRDSS is a very new scale, its translations into other languages were not found in the literature. However, PDSS, which was developed as an alternative to EDSS, provides important data for our study because it is a questionnaire filled by the patient (Kahraman et al., 2021). The PDSS was developed to represent a patient-reported outcome of the effect of MS on walking, while the SRDSS was developed to detect the EDSS interval with a patient-filled scale (Kaufmann et al., 2020; Schwartz et al., 1999).

Since SRDSS is a newly developed questionnaire, no studies have been found in the literature on test-retest reliability. However, our study showed that SRDSS has a high relative test-retest reliability. The mean difference between test-retest evaluations of the Turkish version of the SRDSS is close to zero. These results showed that there was no significant systematic bias between test-retest evaluations (Bland & Altman, 1999). A narrow range of the limits of agreement shown on the Bland-Altman plot indicated that the SRDSS had high stability and low variation between the two assessments (Bland & Altman, 1986). The Turkish version of the SRDSS is a convenient tool for estimating EDSS categories as a result of three simple questions. These questions can be answered quickly and self-reported answers can be given orally, online or on paper. This brevity and flexibility could potentially reduce the underrepresentation of people with MS who are severely disabled, elderly, or living in hard-to-reach areas. In such cases, results of SRDSS can help contextualize by including in a rough estimate of mobility-centered findings.

The number of participants who were not in the correct EDSS range according to SRDSS values was 3 (2.34%). While the EDSS value of one of these participants was 4, the EDSS value was found to be 3.5 or less according to the SRDSS. While the EDSS values of the other two participants were 3.5, the EDSS value was found to be between 4 and 6.5 according to SRDSS. We think that this may be due to the fact that one of the main parameters in the definition of EDSS 4 is walking more than 500 meters and the intermediate walking distance limit of SRDSS is 500 meters (Kaufmann et al., 2020; Kurtzke, 1983). It is known that there may be a slight error in the estimation of the daily walking distance of the patients (Skjerbæk et al., 2019). For this reason, the highest error in the self-responses of the participants may be in these intermediate values.

Our study had several limitations. First of all, the individuals participating in our study may have cognitive disorders. Therefore, this situation may affect our results. It seems plausible that the ability to predict walking performance is affected in patients with evident cognitive deficits. However, since most of the participants had low EDSS values, we think that cognitive impairment is low. In conclusion, we emphasize the need for cognitive assessment in future SRDSS validity and reliability studies. Second, we recruited our participants from a single centre. However, most of the participants had RRMS and low EDSS scores. This meant that most of the participants did not have a serious gait disturbance. As a result of these reasons, SRDSS shows a high floor effect. Therefore, future studies homogeneously distributed by disability levels in individuals with MS may further support the validity of the SRDSS. Consequently, all these reasons may limit the generalizability of our results.

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Conflict of Interest

The author declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Author Contributions

Plan, design: FB, CFD**; Material and methods:** FB **Data analysis and comments:** FB**; Writing and corrections:** FB, CFD.

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