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## WORK STATUS AND FACTORS AFFECTING WORK ENGAGEMENT OF PEOPLE WITH MULTIPLE SCLEROSIS

*RADNI STATUS I FAKTORI KOJI UTIČU NA RADNO ANGAŽOVANJE OBOLELIH OD MULTIPLE SKLEROZE*

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### Summary

**Introduction.** Regular follow-up and support of people with multiple sclerosis in finding and keeping employment may enable them to stay employed longer and have better quality of work life, financial security, and a higher degree of social participation. The objective of this study was to determine the work status and factors that may affect work engagement of people with multiple sclerosis. **Material and Methods.** The study was conducted in the territory of the Autonomous Province of Vojvodina, and included 108 subjects with relapsing-remitting multiple sclerosis, aged 18 - 65 years, using the expanded disability status scale, 0 - 5.5. The data were collected using a General questionnaire and the multiple sclerosis work difficulties questionnaire. **Results.** Out of 108 subjects, only 37 were employed or had been retired for less than three years, which were the criteria for filling out the multiple sclerosis work difficulties questionnaire (in Serbian). Our results showed that subjects perceived cognitive difficulties and movement/mobility difficulties as the main factors affecting their work performance. **Conclusion.** The analysis of environmental factors and factors affecting work engagement of people with multiple sclerosis showed that other factors affected their work more than their personal preferences or the disease itself.

**Key words:** Multiple Sclerosis; Disabled Persons; Employment; Work Capacity Evaluation; Social Participation; Surveys and Questionnaires; Quality of Life

### Introduction

Multiple sclerosis (MS) is a chronic, unpredictable neurological disease, and its onset is usually between 20 and 40 years [1], during the period of peak professional life development. It is one of the most common causes of disability among young people in Europe [2]. However, certain symptoms, acceptance of diagnosis, phases of exacerbations and numerous other circum-

### Sažetak

**Uvod.** Adekvatnim načinom praćenja i podrškom prilikom zaposlenja i tokom radnog angažovanja, osobama obolelim od multiple skleroze omogućuje se duži i kvalitetniji ostanak na poslu, finansijska sigurnost i veći stepen socijalne participacije. Cilj rada je bio da utvrdimo radni status i faktore koji mogu uticati na radno angažovanje obolelih od multiple skleroze. **Materijal i metode.** Istraživanje je sprovedeno na teritoriji Autonomne Pokrajine Vojvodine na ukupnom uzorku od 108 ispitanika sa relapsno-remitentna formom multiple skleroze, starosti 18–65 godina i EDSS skorom 0–5,5. Podaci su prikupljeni Opštim upitnikom i *The Multiple Sclerosis Work Difficulties Questionnaire* – MSWDQ koji je preveden i prilagođen za potrebe srpskog govorno-jezičkog područja. **Rezultati.** Od ukupnog uzorka (n = 108), svega 37 obolelih od multiple skleroze radi ili je u penziji manje od tri godine što je bio preduslov popunjavanja upitnika. Utvrđeno je da ispitanici kognitivne teškoće i teškoće sa pokretljivošću percipiraju kao glavne teškoće odnosno faktore koji utiču na obavljanje posla. **Zaključak.** Analizirajući faktore okruženja i faktore koji utiču na radno angažovanje obolelih od multiple skleroze, zaključili smo da drugi faktori više utiču na rad ispitanika sa multiplom sklerozom, nego njihova lična želja ili sama bolest.

**KLjučne reči:** multipla skleroza; osobe sa invaliditetom; zapošljavanje; procena radnih sposobnosti; socijalna participacija; ankete i upitnici; kvalitet života

stances, affect the individual's perception of life, present job, decision to find a new employment, and ability to function on daily basis. Moreover, prior studies indicate that both physical and cognitive functional limitations associated with MS are likely the main factors of work ability or work status (i.e. being paid vs. not paid) [3] as well as of the type of employment. Employment is an important issue for people with MS, because it directly affects the individual's level of social participation. Data show that employed people with MS have a better quality of life [4]. Furthermore, physical and cognitive functional limitations associated with the disease are probably the main determinants of work ability [3].

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**Abbreviations**

MS	– multiple sclerosis
EDSS	– expanded disability status scale
MSWDQ	– Multiple Sclerosis Work Difficulties Questionnaire
SPSS	– Statistical Package for the Social Sciences
AM	– arithmetic mean

Serbia has a formal legal framework for employment of disabled people, including people with MS. The institutional and legal framework is in line with international recommendations and trends regarding people with disability. Currently, there is an employment quota system for disabled people. The law enables rehabilitation, facilitated employment, special forms of employment, and work engagement of disabled people [5–8].

However, due to absence of other important measures, neither getting nor keeping a job has been made easier for people with MS.

International studies indicate that more than 50% of all people with MS are unemployed [9, 10], while in Serbia, the number of unemployed people with MS is unknown.

In order to understand the work-related perceptions of people with MS better, the Multiple Sclerosis Work Difficulties Questionnaire (MSWDQ) was created [11]. It was developed using an Australian sample, a comprehensive 50-item questionnaire assessing 12 domains of workplace difficulties, each of which were highly predictive workplace outcomes and/or expectations about future employment. Difficulties experienced in the workplace, stemming directly or indirectly from MS, are therefore seen to play a key role in making a decision to withdraw from work. The perceptions of workplace difficulties of people with MS in Serbia have not been examined. Such examinations are of crucial importance, not only to understand the types of difficulties experienced by Serbian people with MS better, but also to highlight the difficulties which might exclusively be related to employment outcomes, such as work withdrawal. This information in turn is highly important for providing effective vocational and rehabilitation programs in the Serbian community within the legal context.

The aim of this study was twofold: firstly to validate and pilot the use of a translated version of the MSWDQ for MS population in Serbian language, and secondly to conduct a pilot study on the relationships between various workplace difficulties and disease-related factors and demographic variables. Such an examination should highlight factors which most likely affect work engagement in people with MS in Serbia.

**Material and Methods**

The study was carried out in the territory of the Autonomous Province of Vojvodina, Serbia, and included an initial sample of 108 subjects with relapsing-remitting MS. Of the 108 subjects, however, 71 participants were excluded, because they had not been employed within the last three years. Another 3 participants were excluded due to missing data on some items. The final sample comprised 34 people with MS, aged 18 - 65 years ( $M = 40$ ;  $SD = 8.2$ ), with the EDSS

0 - 5.5. All included subjects had been diagnosed with MS at least one year before the study. The data were collected using a General questionnaire designed for the purpose of the study.

The MSWDQ [11] was translated and adapted for use in the Serbian speaking population, and completed by participants. This translation into the Serbian language specifically involved synthesis of the translated version, evaluation of the synthesized version by experts, evaluation by a target group, and back translation as recommended by Gjersing, Caplehorn, and Clausen [12]. The MSWDQ has 12 subscales or workplace difficulty domains related to:

- a. psychological/cognitive barriers: general cognitive difficulties, prospective memory difficulties, fatigue, low self-esteem, interpersonal difficulties, and non-supportive workplace;
- b. physical barriers: movement/mobility difficulties, workplace inaccessibility, pain/temperature difficulties, and bladder/bowel difficulties; and
- c. external barriers: financial security concerns and work/home balance difficulties.

The MSWDQ has a total of 50 items, and participants were asked to rate the extent of work difficulties during the previous 4 weeks at the current or previous job. The responses were graded on a 5-point Likert scale, from 0 (never) to 4 (almost always). Thus, higher responses showed an increased perception of disease-related difficulties. Both MSWDQ total and individual subscale scores were examined. The MSWDQ demonstrated good to excellent levels of internal consistent (Cronbach's alpha ranges for the individual subscales range from .74 to .92), and demonstrated good concurrent validity in relation to past withdrawal from work.

The Kurtzke Functional Systems and EDSS (Kurtzke, 1983) [13] is the most widely used assessment scale for measuring physical disability in MS patients [14]. The disability rating was completed by the patients' neurologist, according to a 10-point scale ranging from 0 (normal neurological function & no disability) to 10 (death due to MS). Intra-rater and inter-rater reliability coefficients for the EDSS were high, with respective coefficients of .95 and .91 [15].

Statistical data analysis was performed using the Statistical Package for the Social Sciences (SPSS) software. Descriptive statistical methods (arithmetic mean, median, range, standard deviation), and normality tests, Kolmogorov-Smirnov and Shapiro-Wilk tests were used. Statistical significance was defined as  $p < 0.05$  [16]. Age differences between the groups were examined using the Mann-Whitney U test. To examine possible biases in the items, item analysis was conducted. Internal consistency, Cronbach's alpha was calculated [17]. Factor analysis with varimax rotation was conducted using principal component analysis in SPSS.

**Results***General questionnaire results*

Women (70/64.8%) were prevalent in the sample. In our sample ( $n = 108$ ), most subjects, i.e., 73 (67.6%) had secondary education, 27 (25%) had tertiary education, while 8 (7.4%) had incomplete or complete ele-

**Table 1.** Reliability of the MSWDQ subscales  
*Tabela 1. Pouzdanost subskala MSWDQ*

Subscales <i>Subskale</i>	Cronbach's $\alpha$ <i>Kronbahov <math>\alpha</math></i>	Item total correlation <i>Ukupna korelacija</i>
General cognitive difficulties/ <i>Opšte kognitivne teškoće</i>	0.82	0.52 – 0.82
Movement/mobility difficulties/ <i>Teškoće sa pokretljivošću</i>	0.77	0.57 – 0.77
Work/home balance difficulties/ <i>Teškoće usklađivanja posao/kuća</i>	0.80	0.57 – 0.80
Non-supportive workplace/ <i>Nedostatak podrške na poslu</i>	0.64	0.56 – 0.79
Bladder /bowel difficulties/ <i>Teškoće sa crevima i bešikom</i>	0.81	0.53 – 0.89
Financial security concerns/ <i>Zabrinutost za finansijsku sigurnost</i>	0.75	0.52 – 0.80
Low self-esteem/ <i>Nisko samopouzdanje</i>	0.60	0.57 – 0.76
Prospective memory difficulties/ <i>Prospektivne poteškoće sa memorijom</i>	0.73	0.51 – 0.86
Workplace inaccessibility/ <i>Nepristupačnost radnog mesta</i>	0.75	0.54 – 0.89
Pain/temperature difficulties/ <i>Teškoće sa bolovima i temperaturom</i>	0.70	0.60 – 0.74
Interpersonal difficulties/ <i>Teškoće u interpersonalnim odnosima</i>	0.60	0.52 – 0.85
Fatigue/ <i>Zamor</i>	0.70	0.53 – 0.75

mentary education. This finding is in agreement with the educational distribution in the studied region. Most subjects ( $n = 70$ ; 64.8%) lived in an urban environment, as opposed to 38 subjects (35.2%) who lived in a rural environment. In regard to the marital status, 71 (68.9%) subjects were married or lived with a partner, 7 (6.6%) were separated or divorced, and 26 (24.5%) were single. Fifty-three subjects had no children, 19 had one child, 31 had two children, and 5 subjects had three or more children. Most subjects (57.8%) had their own place to live. An additional positive factor was that most subjects lived with a partner and children, 19 subjects lived with their parents, and only 10 subjects lived alone (with or without children).

Twenty-eight (26.2%) subjects were employed full-time, 4 (3.7%) were employed part-time, and 47 (43.9%) were retired. Equal number of subjects were unemployed, due to the health status and due to other reasons, 12 (11.2%) each. Only one (0.9%) subject had never looked for a job. The sample included 3 (2.8%) university students. Accordingly, in regard to the income, most subjects lived on a pension or salary, and less than 15% of all subjects were receiving unemployment benefits, such as disability-related financial support or child support. Concerning assistive technology, 63 (58.9%) subjects used some devices, most frequently eyeglasses and walking canes/sticks.

#### *Qualitative analysis of the MSWDQ content*

The time necessary to complete the questionnaire ranged from 20 to 25 minutes. All subjects reported that they understood all questions and reported that the Serbian version of MSWDQ adequately reflected the difficulties they experienced in the workplace, and was easy to complete.

#### *Reliability of the MSWDQ*

The Cronbach's Alpha Reliability Coefficient for the overall MSWDQ was excellent (0.95). The correlation coefficient between the 50 items and the total scale was high, ranging from 0.60 to 0.82. The final

sample comprised 34 people with MS, and the reliability estimates were similar in various MSWDQ subscales (**Table 1**). Inter-item correlations were considered acceptably low, and correlations of items on individual subscales did not exceed 0.90, and together with high Cronbach's  $\alpha$  coefficient, it indicated good psychometric properties of the translated scale.

#### *Validity of the MSWDQ*

Exploratory factor analysis (principal component method) was used to assess the proposed 12-item structure of the questionnaire. Twelve factors were isolated - 10 significant and 2 insignificant (items on the financial security concerns and movement/mobility difficulties subscales). These 10 factors explain 84.94% of the variance of the questionnaire content. The addition of the two factors does not significantly increase the percentage of the explained variance (88.69%).

#### *Exploration of MSWDQ scores*

The mean scores on individual MSWDQ subscales ranged from 33.75 to 62.73. The subjects perceived most difficulties in the domain of financial security, and least difficulties in the domain of prospective memory difficulties (**Table 2**).

#### *Normality of score distribution on the MSWDQ and the subscales*

**Table 3** shows that all MSWDQ subscales, except financial security difficulties, deviate significantly from a normal distribution, so we used non-parametric statistical analysis to analyze differences.

#### *Correlation between the MSWDQ subscales and socio-demographic variables*

The Mann-Whitney U test was used to test sex differences in the 12 MSWDQ subscales. The results showed no gender-based differences associated with workplace problems on any of the 12 subscales.

The Kruskal-Wallis test did not show statistically significant differences ( $p < .05$ ) in workplace difficul-

**Table 2.** The MSWDQ scores**Tabela 2.** Skorovi na upitniku MSWDQ

	Min.	Max.	AM	SD	Skewness Asimetrija	Kurtosis Homogenost distribucije
General cognitive difficulties/ <i>Opšte kognitivne teškoće</i>	25.00	83.33	43.67	14.11	1.11	1.46
Movement/mobility difficulties/ <i>Teškoće sa pokretljivošću</i>	25.00	89.29	48.69	18.36	0.72	-0.51
Work/home balance difficulties <i>Teškoće usklađivanja posao/kuća</i>	25.00	83.33	42.26	16.34	0.81	0.07
Non-supportive workplace/ <i>Nedostatak podrške na poslu</i>	25.00	75.00	37.67	13.50	1.54	1.89
Bladder/bowel difficulties/ <i>Teškoće sa crevima i bešikom</i>	25.00	112.50	45.75	23.45	1.21	0.87
Financial security concerns <i>Zabrinutost za finansijsku sigurnost</i>	25.00	118.75	62.93	26.87	0.34	-0.86
Low self-esteem/ <i>Nisko samopouzdanje</i>	25.00	75.00	44.01	18.60	0.55	-1.30
Prospective memory difficulties <i>Prospektivne poteškoće sa memorijom</i>	25.00	65.00	33.75	11.67	1.28	.83
Workplace inaccessibility/ <i>Nepristupačnost radnog mesta</i>	25.00	87.50	34.72	16.29	2.13	4.28
Pain/temperature difficulties <i>Teškoće sa bolovima i temperaturom</i>	25.00	91.67	40.80	19.71	1.43	1.37
Interpersonal difficulties <i>Teškoće u interpersonalnim odnosima</i>	25.00	83.33	33.88	14.99	1.87	3.03
Fatigue/ <i>Zamor</i>	25.00	100.00	46.71	19.42	1.18	1.56

ties between subjects with different educational levels or marital status, and age was also not significantly associated with perceived workplace difficulties.

The time since diagnosis, in our subjects ranged from 1 to 22 years (arithmetic mean (AM) = 3.49) and time since symptom onset was 1 - 31 years (AM = 11.23). Time since diagnosis significantly negatively correlated with the following domains/subscales: non-supportive workplace ( $r = -0.35$ ,  $p = 0.03$ ), bowel/bladder difficulties ( $r = -0.43$ ,  $p = 0.00$ ), and interpersonal difficulties ( $r = -0.37$ ,  $p = 0.02$ ). These correlations reflect the pattern that the earlier the diagnosis was made, the more difficulties the patient had in these domains.

The time since symptom onset significantly negatively correlated with the following domains/subscales: home/work balance difficulties ( $r = -0.33$ ,  $p = 0.04$ ), non-supportive workplace ( $r = -0.36$ ,  $p = 0.02$ ), bowel/bladder difficulties ( $r = -0.34$ ,  $p = 0.03$ ), and interpersonal difficulties ( $r = -0.37$ ,  $p = 0.02$ ). The negative correlation means that the earlier the onset of symptoms, the patients had more difficulties in these domains.

There was a significant difference between subjects living in urban and rural environments, regarding the severity of difficulties in the following domains: general cognitive difficulties, non-supportive workplace, low self-esteem, and prospective memory difficulties (**Table 4**). The mean values show that subjects from rural environments reported more difficulties in

**Table 3.** Tests of normality of distribution**Tabela 3.** Testovi normalnosti raspodele

	Kolmogorov-Smirnov		
	statistic	df	p
Movement/mobility difficulties/ <i>Teškoće sa pokretljivošću</i>	0.17	26	0.03
Work/home balance difficulties/ <i>Teškoće usklađivanja posao/kuća</i>	0.16	26	0.07
Non-supportive workplace/ <i>Nedostatak podrške na poslu</i>	0.20	26	0.00
Bladder /bowel difficulties/ <i>Teškoće sa crevima i bešikom</i>	0.20	26	0.00
Financial security concerns/ <i>Zabrinutost za finansijsku sigurnost</i>	0.21	26	0.00
Low self-esteem/ <i>Nisko samopouzdanje</i>	0.11	26	0.20
Prospective memory difficulties/ <i>Prospektivne poteškoće sa memorijom</i>	0.23	26	0.00
Workplace inaccessibility/ <i>Nepristupačnost radnog mesta</i>	0.26	26	0.00
Pain/temperature difficulties/ <i>Teškoće sa bolovima i temperaturom</i>	0.27	26	0.00
Interpersonal difficulties/ <i>Teškoće u interpersonalnim odnosima</i>	0.22	26	0.00
Fatigue/ <i>Zamor</i>	0.36	26	0.00
Movement/mobility difficulties/ <i>Teškoće sa pokretljivošću</i>	0.14	26	0.14

**Table 4.** Association between urban/rural environment and workplace difficulties  
**Tabela 4.** Urbana ili ruralna sredina u odnosu na domene teškoća pri radu

Subscale/Supskale	Environment/Sredina	Mean Rank Srednji stepen	Test statistic Statistika testa	P
General cognitive difficulties <i>Opšte kognitivne teškoće</i>	Urban/Urbana	17.04	Z* = 71.00	p = 0.04
	Rural/Ruralna	25.11		
Non-supportive workplace <i>Nedostatak podrške na poslu</i>	Urban/Urbana	16.07	Z = 56.00	p = 0.01
	Rural/Ruralna	25.78		
Low self-esteem <i>Nisko samopouzdanje</i>	Urban/Urbana	16.34	Z = 51.50	p = 0.00
	Rural/Ruralna	27.28		
Prospective memory difficulties <i>Prospektivne poteškoće sa memorijom</i>	Urban/Urbana	17.02	Z = 70.50	p = 0.04
	Rural/Ruralna	25.17		

Z\* = Mann-Whitney test/Man-Vitnijev test

these four domains compared to subjects from urban environments.

#### *Correlation between the MSWDQ subscales and the EDSS*

The Spearman's correlation coefficient was used to test the association between the MSWDQ subscales and the EDSS. The results (**Table 5**) showed a significant association between the pyramidal function and movement/mobility difficulties ( $r = 0.41$ ,  $p = 0.01$ ). In addition, there was a significant association between the cerebellar function and interpersonal difficulties ( $r = 0.35$ ,  $p = 0.03$ ). Also, the bowel and bladder function was significantly associated with the following domains: movement/mobility difficulties ( $r = 0.36$ ,  $p = 0.02$ ), bowel/bladder difficulties ( $r = 0.63$ ,  $p = 0.00$ ), financial security concerns ( $r = 0.33$ ,  $p = 0.04$ ), workplace inaccessibility ( $r = 0.44$ ,  $p = 0.00$ ), pain/temperature difficulties ( $r = 0.35$ ,  $p = 0.03$ ), and fatigue ( $r = 0.40$ ,  $p = 0.01$ ).

#### **Discussion**

Employment continues to be of concern in persons with MS. However, few researches have been done in Serbian population to examine factors that may result in withdrawal from employment. Based on this, the aims of this study were to determine the work status and factors that may affect work engagement of people with MS.

The MSWDQ in Serbian was easy to use and our subjects completed it in less than 25 minutes. There were almost no comprehension difficulties. Internal consistency for all items was very high, which was generally in agreement with original scale developed in the Australian sample [11].

Work is an important aspect of human life, because besides livelihood it provides a feeling of self-respect, possibilities for independent life, and complete integration in the social community. Progressive diseases, such as MS, lead to difficulties in finding and keeping employment, thus affecting the

**Table 5.** Correlations between the MSWDQ subscales and EDSS function domains/total EDSS

**Tabela 5.** Povezanost skala upitnika MSWDQ sa skorovima na funkcionalnim domenima i ukupnom Skalom za procenu neurološkog deficita

Spearman rank correlation/Spirmanova korelacija ranga												
EDSS	GCD	MMD	WBD	NSW	BBD	FSC	LSE	PMD	WI	PTD	ID	FA
Visual/Vizuelni	-0.10	-0.14	-0.21	-0.31	-0.26	-0.26	-0.17	0.06	-0.22	-0.32	0.07	-0.23
Brainstem/Moždano stablo	-0.04	0.10	0.11	0.32	0.13	0.25	-0.00	0.03	0.11	0.12	-0.09	0.14
Pyramidal/Piramidalni	0.04	0.41*	0.21	-0.09	0.24	0.06	0.21	0.03	0.32	0.28	0.31	0.20
Cerebellar/Cerebelarni	0.08	0.23	0.08	-0.10	0.14	-0.10	-0.01	-0.14	0.22	0.08	0.35*	0.01
Sensory/Senzorni	-0.16	0.09	-0.05	0.12	0.09	0.19	0.00	-0.04	0.23	0.24	-0.04	0.16
Bowel and bladder	-0.04	0.36*	0.20	0.23	0.63**	0.33*	0.12	-0.03	0.44**	0.35*	0.26	0.40*
EDSS score/EDSS skor za RAP creva i bešike	-0.17	0.25	-0.07	-0.06	0.04	0.01	-0.08	-0.06	0.18	0.14	0.06	0.16

\* significant at  $p < 0.05$ ; \*\* significant at  $p < 0.01$

Legend: GCD - General cognitive difficulties; MMD - Movement/mobility difficulties; WBD - Work/home balance difficulties; NSW - Non-supportive workplace; BBD - Bladder /bowel difficulties; FSC - Financial security concerns; LSE - Low self-esteem; PMD - Prospective memory difficulties; WI - Workplace inaccessibility; PTD - Pain/temperature difficulties; ID - Interpersonal difficulties; FA - Fatigue

Legenda: GCD - Opšte kognitivne teškoće; MMD - Teškoće s pokretljivošću; WBD - Teškoće usklađivanja posao/kuća; NSW - Nedostatak podrške na poslu; BBD - Teškoće sa crevima i bešikom; FSC - Zabrinutost za finansijsku sigurnost; LSE - Nisko samopouzdanje; PMD - Prospektivne poteškoće s memorijom; WI - Nepristupačnost radnog mesta; PTD - Teškoće sa bolovima i temperaturom; ID - Teškoće u interpersonalnim odnosima; FA - Zamor

degree of social participation. MS is associated with a high unemployment rate (50 – 60% of all patients) [10, 18]. Literature data show that most people with MS want to return to work [10, 19]. However, this is contrary to the trend in Serbia, where most people suffering from MS want to retire, in the light of the workforce in an unpredictable market.

Our study included significantly more women than men with MS. The disease, disability and the woman's role in the society, certainly affect professional life and represent a barrier in making a career when suffering from MS. A study published in 2000 [20], found that 60% of women with MS believed that lack of energy to meet all domestic and professional demands due to MS was a sufficient reason to leave employment. Personal factors also significantly influence a person's ability to cope with demands and needs of work.

The unemployment rate in people with MS increases with age, significantly more than in the general population, and according to the literature data it is attributed to increased disability [20]. The average age of our subjects was about 40 years, which is a productive age when a person should achieve professional self-actualization.

The professional status of people with MS is similar to that of the general population, since most have secondary or tertiary education and previous work experience. Even literature data from the last century confirmed that higher education was a protective factor against unemployment [21, 22]. Almost 65% of all subjects in our study came from an urban environment, which should also be a positive aspect of employment retention because it excludes commuting to work and increases chances of choosing a workplace.

Disease duration and progression have been proved to be predictive factors of the work status [18], which was partly confirmed by our study.

Due to its validity and reliability, the MSWDQ was suitable for this research. The questionnaire scores need further discussion. Although we did not find a statistical significance for the financial security concerns subscale, it is important to note that people with MS do perceive the existence of disease-related financial difficulties. In a national study of the economic impact of MS on families, Catanzaro and Weinert [23] found that 21% of families had inadequate incomes to cover medical expenses and 25% did not have sufficient means to satisfy basic living costs. In original MSWDQ, financial concerns were not predictive of work outcomes.

In the present study, the subscales that showed a high statistical significance may be grouped into subscales whose items relate to external factors – work environment (non-supportive workplace, workplace inaccessibility, interpersonal difficulties) and those whose items relate to internal factors – problems due to MS (memory difficulties, bowel/bladder difficulties, low self-esteem, pain/temperature difficulties). The results of previous similar studies also identified external factors as influential and emphasized the negative influence of poorly adjusted work structure for people with MS. This includes physical barriers,

such as a lack of accommodation in the workplace or inaccessible bathrooms, inflexible work schedules and a lack of support from the employer and colleagues [24]. Our results obtained on the work environment subscales show that our subjects perceived their workplace as sufficiently supportive and accessible and had no interpersonal difficulties.

When the work status and workplace difficulties of people with MS are observed through the prism of disease and disability, it is important to consider how the EDSS, i.e. objective neurological deficit, contributes to our understanding of different domains of professional functioning of people with MS. We found a significant association between pyramidal function and mobility difficulties. Mobility difficulties may include commuting to work or workplace accessibility and spatial organization, and it is therefore not surprising that mobility is the factor that most significantly affects work hours and work ability. This was also confirmed by previous researches [25, 26]. The association of the recorded cerebellar deficits with interpersonal difficulties indicates that cognitive/mental dysfunction impairs communication at work through attention and memory problems, which was also reported by previous studies [27, 28]. These findings emphasize the importance of interpersonal relationships for job retention.

In our study, the bowel/bladder function was significantly associated with different difficulties at work, which results from the patient's fear of incontinence. This was recognized in previous studies as well [20, 29].

Although supportive measures for people with disability, including workplace accommodation and equipment, are available in Serbia, most subjects in our study did not need complex assistive devices.

Social and occupational position and factors affecting social participation of people with MS have not been studied so far in Serbia. Furthermore, no disease-specific questionnaires targeting different aspects of employment of people with MS have been used. However, considering that new definitions of disability presuppose taking into consideration the whole person, it is clear that only adequate functional assessment and rehabilitation of motor, cognitive and social abilities may enable full social participation and work engagement of people with MS.

A limitation of the present study was a small sample size and the lack of additional instruments for detection of potential cognitive and behavioral problems/impairments. For this reason, individuals who had not been working for more than three years were not eligible to fill out the questionnaire, because the data validity would be questionable, considering that a high percentage of people with MS may have unrecognized or underestimated their cognitive impairment/s. However, the goal of this pilot study was to translate the instrument and verify item performance before undertaking major data collection, and this was accomplished. The final version of the MSWDQ-Serbian is correct and idiomatic and may be widely used. It may provide faster and easier detection of workplace problems in people with MS and thus enable supportive measures for their employment retention.

## Conclusion

The results suggest that people with multiple sclerosis are part of the global employment competition, and our analysis of environmental factors and factors affecting work engagement of people with multiple sclerosis showed that other factors affected their work more than their preferences or the disease. Further research in this field is required to define mechanisms that would solve practical problems affecting employment of persons with multiple sclerosis.

After adapting the multiple sclerosis work difficulties questionnaire to the Serbian language and cultural characteristics, we have obtained an instrument that does not differ much from the original English version. The final version of the multiple sclerosis work difficulties questionnaire-Serbian demonstrates satisfactory internal consistency and reliability. We have proved that the multiple sclerosis work difficulties questionnaire may be used in different countries.

## References

1. Compston A, Coles A. Multiple sclerosis. *Lancet*. 2008;372(9648):1502-17.
2. Moore P, Harding KE, Clarkson H, Pickersgill TP, Wardle M, Robertson NP. Demographic and clinical factors associated with changes in employment in multiple sclerosis. *Mult Scler*. 2013;19(12):1647-54.
3. Pompeii LA, Moon SD, McCrory DC. Measures of physical and cognitive function and work status among individuals with multiple sclerosis: a review of the literature. *J Occup Rehabil*. 2005;15(1):69-84.
4. Miller A, Dishon S. Health-related quality of life in multiple sclerosis: the impact of disability, gender and employment status. *Qual Life Res*. 2006;15(2):259-71.
5. Zakon o profesionalnoj rehabilitaciji i zapošljavanju osoba sa invaliditetom. *Službeni glasnik RS*. 2009;(36):205-10.
6. Pravilnik o bližem načinu, troškovima i kriterijumima za procenu radne sposobnosti i mogućnosti zaposlenja ili održanja zaposlenja osoba sa invaliditetom. *Službeni glasnik RS*. 2010;(36).
7. Pravilnik o bližim uslovima, kriterijumima i standardima za sprovođenje mera i aktivnosti profesionalne rehabilitacije. *Službeni glasnik RS*. 2009;(112).
8. Pravilnik o načinu praćenja izvršavanja obaveze zapošljavanja osoba sa invaliditetom i načinu dokazivanja izvršavanja te obaveze. *Službeni glasnik RS*. 2010;(33).
9. Simmons RD, Tribe KL, McDonald EA. Living with multiple sclerosis: longitudinal changes in employment and the importance of symptom management. *J Neurol*. 2010;257(6):926-36.
10. Julian LJ, Vella L, Vollmer T, Hadjimichael O, Mohr DC. Employment in multiple sclerosis. Exiting and re-entering the work force. *J Neurol*. 2008;255(9):1354-60.
11. Honan CA, Brown RF, Hine DW, Vowels L, Wollin JA, Simmons RD, et al. The multiple sclerosis work difficulties questionnaire. *Mult Scler*. 2012;18(6):871-80.
12. Gjersing L, Caplehorn JR, Clausen T. Cross-cultural adaptation of research instruments: language, setting, time and statistical considerations. *BMC Med Res Methodol*. 2010;10:13.
13. Kurtzke JF. Rating neurologic impairment in multiple sclerosis: an expanded disability status scale (EDSS). *Neurology*. 1983;33(11):1444-52.
14. Sharrack B, Hughes RA. The Guy's Neurological Disability Scale: a new disability measure for multiple sclerosis. *Mult Scler*. 1999;5(4):223-33.
15. Ravnborg M, Gronbech-Jensen M, Jonsson A. The MS Impairment Scale: a pragmatic approach to the assessment of impairment in patients with multiple sclerosis. *Mult Scler*. 1997;3(1):31-42.
16. Fajgelj S. Psihometrija metod i teorija psihološkog merenja. Beograd: Centar za primenjenu psihologiju; 2009.
17. Cronbach LJ. Coefficient alpha and the internal structure of tests. *Psychometrika*. 1951;16(3):297-334.
18. Strober L, Chiaravalloti N, Moore N, DeLuca J. Unemployment in multiple sclerosis (MS): utility of the MS Functional Composite and cognitive testing. *Mult Scler*. 2014;20(1):112-5.
19. O'Connor RJ, Cano SJ, Torrenta L, Thompson AJ, Playford ED. Factors influencing work retention for people with multiple sclerosis: cross-sectional studies using qualitative and quantitative methods. *J Neurol*. 2005;252(9):892-6.
20. Dyck I, Jongbloed L. Women with multiple sclerosis and employment issues: a focus on social and institutional environments. *Can J Occup Ther*. 2000;67(5):337-46.
21. La Rocca N, Kalb R, Kendall P, Scheinberg L. The role of disease and demographic factors in the employment in people with multiple sclerosis. *Arch Neurol*. 1982;39(4):256.
22. Patti F, Pozzilli C, Montanari E, Pappalardo A, Piazza L, Levi A, et al. Effects of education level and employment status on HRQoL in early relapsing-remitting multiple sclerosis. *Mult Scler*. 2007;13(6):783-91.
23. Catanzaro M, Weinert C. Economic status of families living with multiple sclerosis. *Int J Rehabil Res*. 1992;15(3):209-18.
24. Johnson KL, Klasner ER, Amtmann D, Kuehn CM, Yorkston KM. Medical, psychological, social, and programmatic barriers to employment for people with multiple sclerosis. *J Rehabil*. 2004;70(1):38-49.
25. Johnson KL, Bamer AM, Fraser RT. Disease and demographic characteristics associated with unemployment among working-age adults with multiple sclerosis. *Int J MS Care*. 2009;11(3):137-43.
26. Salter AR, Cutter GR, Tyry T, Marrie RA, Vollmer T. Impact of loss of mobility on instrumental activities of daily living and socioeconomic status in patients with MS. *Curr Med Res Opin*. 2010;26(2):493-500.
27. Smith MM, Arnett PA. Factors related to employment status changes in individuals with multiple sclerosis. *Mult Scler*. 2005;11(5):602-09.
28. Sweetland J, Riazzi A, Cano SJ, Playford ED. Vocational rehabilitation services for people with multiple sclerosis: what patients want from clinicians and employers. *Mult Scler*. 2007;13(9):1183-9.
29. Roessler RT, Rumrill PD Jr. Multiple sclerosis and employment barriers: a systemic perspective on diagnosis and intervention. *Work*. 2003;21(1):17-23.

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