#### RESEARCH PAPER



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# Vocational activity for patients with multiple sclerosis

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#### **ABSTRACT**

**Introduction.** Multiple sclerosis (MS) usually occurs in young adults and, due to its long-lasting course and variety of symptoms, can affect their vocational activity. Our study aimed to evaluate employment status and working activity for persons with MS with regard to disease-related factors, quality of life, and depression.

Material and methods. 250 subjects with MS (62 men, 188 women, aged 19–71 years, mean 42.2) responded to a survey into various aspects of their employment. Relationships were sought between work-related issues and disease-related variables [MS type and duration, major symptoms, disability level on the Expanded Disability Status Scale (EDSS)], quality of life (WHOQOL-BREF, World Health Organisation Quality of Life brief questionnaire) and depression (BDI, Beck Depression Inventory). Statistical analysis included Mann-Whitney U, Student's t, and Pearson's chi-squared tests.

**Results.** 71.2% of the patients were employed, and 49.1% perceived an impact of the disease upon their working activity (i.e. job loss, problems with finding a new one, and/or forced change of type and/or character of employment). Unemployed subjects had higher EDSS scores (4.05 vs. 2.34, p < 0.001) and longer disease durations (13.6 vs. 9.4, p < 0.001) than employed ones. They also scored higher on BDI (15.4 vs. 9.05, p < 0.001) and lower in all domains of WHOQOL-BREF (p < 0.001).

**Conclusions.** The consequences of MS negatively influence many work-related factors. Unemployment is associated with a higher frequency of depression and a lower quality of life in MS patients.

Key words: multiple sclerosis, disability, employment, quality of life, depression

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## Introduction

Multiple sclerosis (MS) is a chronic, immune-mediated disease of the central nervous system, which causes multifocal damage and accumulating disability. Due to a usual young age at onset, its long-lasting and often unpredictable course, and its variety of symptoms (motor, sensory, autonomic, cognitive etc.) [1], MS profoundly affects patients' quality of life, and has a considerable impact upon their social functioning. These issues have already been considered as a substantial outcome of the disease's management.

Among the aspects of social functioning, vocational activity is especially noteworthy. Employment provides economic stability, which determines the standard of living (including healthcare opportunities and lifestyle choices). Moreover, it is a source of satisfaction and self-esteem [2–6].

The impact of MS upon vocational issues includes absenteeism, reduced working hours, change in responsibilities, transitions of employment status, earlier retirement, and ultimately loss of work [7, 8]. Due to the disease's specificity, the percentage of people with MS who are employed is lower than for other chronic disorders [9].

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# Clinical rationale for study

The purpose of this study was to evaluate the employment status and vocational activity of persons with MS and their relationships with disease-related factors, quality of life, and depression.

# Material and methods

The patients recruited for our study remained under the care of the Department of Neurology, University Clinical Hospital or the MS outpatient clinic in the Regional Specialist Hospital and attended follow-up visits in February, March and April 2019. Inclusion criteria comprised a diagnosis of MS (according to the McDonald criteria [10]) and a complete history of the disease documented in medical records. From a group of 302 consecutive patients, after excluding those patients with cognitive impairment who were not able to complete the questionnaire (n = 11), and after eliminating incomplete responses to the survey (n = 41), 250 MS subjects (62 men, 188 women, aged 19–71 years, mean 42.2) were included in the study.

All participants answered a self-administered questionnaire on demographic data, various aspects of employment, job characteristics, and the disease's influence upon these. The latter section included: the subjective perception of MS as a handicap to their current job performance or the search for a new one, disclosure of the disease to the respondent's supervisor/employer, and the availability of any work facilitation due to the disease. The World Health Organisation Quality of Life brief questionnaire (WHOQOL-BREF) [11] was used to evaluate the quality of life, and the Beck Depression Inventory (BDI) [12] was used to assess symptoms of depression. Disease-related variables (MS type and duration, major symptoms and signs, degree of disability on the Expanded Disability Status Scale (EDSS)) [13] were established on the basis of medical records.

The local Bioethical Committee approved the study, and all the subjects provided their informed consent to participate.

MS-related variables, and the results of BDI and WHOQOL-BREF, were compared between the employed and unemployed subjects, and between those who admitted and those who denied an impact of the disease upon their working activity.

Statistical analysis included Mann-Whitney U, Student's t, and Pearson's chi-squared tests. The analyses were performed using Statistica ver. 13.3 (StatSoft Inc., Tulsa, OK, USA).

### Results

# Clinical and demographic characteristics

227 (90.7%) patients had relapsing-remitting and 23 (9.27%) had secondary progressive MS. The mean EDSS score was 2.84 (SD = 1.63). The most debilitating symptoms of MS reported by the patients were fatigue (73.6% of responders) and balance problems (56.8%); the detailed data is set out in Supplementary Table 1.

The main group had a university education (44.8%); detailed educational status is set out in Supplementary Table 2. 75 (30%) respondents lived in rural areas, 86 (34.4%) in towns, and 89 (35.6%) in cities.

## **Employment status**

178 (71.2%) patients were employed and 72 (28.8%) were not; detailed information about employment status is set out in Table 1.

Almost half of the respondents (49.1%) stated that MS and/or its treatment had had a significant impact on their working activity. Fifty subjects claimed that the disease made it difficult to find a job. Thirty-one respondents declared that

Table 1. Characteristics of employment in study group of MS patients

Employment status				
	Employed (n = 178)	Full time (n = 147; 82%) Part time (n = 17; 9.60%)		
		Self-employed ( $n = 14; 7.70$ )		
	Not employed $(n = 72)$	Disability pension (n = 45; 62.5%)		
		Retirement pension ( $n = 6$ ; 8.3%)		
		Unemployment (n = 20; 27.7%)		
		Student (n = 1; 1.3%)		
Duration of employment	Overall	16.6 ± 10.1 years		
	After diagnosis	8.71 ± 5.81 years		
Type of employment	White -collar	109 responders (61.1% of working patients)		
	Manual work	33 responders (18.5% of working patients)		
	Mixed work	34 responders (19.1% of working patients)		
Change of workplace during last two years	Change of workplace/employer	22 responders (12.4% of working patients)		
	Change of type of job	9 responders (5.1% of working patients)		
	Promotion	5 responders (2.8% of working patients)		

Table 2. Incidence of most debilitating MS symptoms with regard to perceived disease impact upon working activity

Most debilitating symptoms of MS			toms of disease or treatment nce your working activity?		φ
		Yes¹	No <sup>2</sup>		
Mobility problems	Yes	46.6%	18.9%	18.3**	0.30
	No	53.4%	81.1%		
Fatigue	Yes	84.5%	64.2%	11.3**	0.23
	No	15.5%	35.9%		
Pain	Yes	42.2%	22.6%	9.59 <sup>*</sup>	0.21
	No	57.8%	77.4%		
Urinary and/or bowel incontinence	Yes	20.9%	6.60%	8.55 <sup>*</sup>	0.20
	No	79.6%	93.4%		
Balance impairment	Yes	66.0%	46.2%	8.3*	0.20
	No	34.0%	53.8%		
Speech disturbances	Yes	14.6%	6.60%	3.51	0.13
	No	85.4%	93.4%		
Tremor	Yes	21.4%	13.2%	2.43	0.11
	No	78.6%	86.8%		
Visual deficit	Yes	45.63%	37.74%	1.34	0.080
	No	54.37%	62.26%		
$^{1}N = 106$ ; $^{2}N = 103$ ; $\chi^{2}$ —result of chi-squ	ıared test; φ — phi o	coefficient; *p < 0.05; **p < 0.001			

the disease had forced them to change the type of job they did, and 40 (22%) said it had required them to reduce their working hours.

Out of the 36 MS subjects who had recently lost their jobs, 21 (58.3%) claimed this had been due to the disease's symptoms. MS was declared as the reason for a disability pension or unemployment by 62 subjects (82.67% of those not employed).

128 respondents (71.9% of all those employed) had disclosed their disease to their employer/supervisor and 112 (67.1%) to co-workers. Among these, 63 were allowed some facilitation in their workplace (in 35 cases flexibility of work schedule, in 15 a home-office option, in 21 adaptation of the workplace to account for their disability, and in two cases, other forms of facilitation).

# Employment status and MS-related factors

Unemployed patients, compared to the employed ones, had higher EDSS scores (4.05 vs. 2.34, p < 0.001,  $\eta 2 = 0.21$ ) and longer disease durations (13.6 vs. 9.4, p < 0.001,  $\eta 2 = 0.05$ ). Those who perceived an influence of the disease on their work activity, compared to those who did not, had higher EDSS scores (2.96 vs. 2.30, p = 0.002, d = -0.44). These two subgroups also differed in the frequency of the most debilitating MS symptoms (Tab. 2).

# Employment and quality of life

Unemployed subjects, compared to employed ones, scored lower in all four domains of WHOQOL-BREF,

reaching statistical significance in all of them: physical domain (p < 0.001,  $\eta 2 = 0.14$ ), psychological domain (p < 0.001,  $\eta 2 = 0.06$ ), social relationships (p < 0.001,  $\eta 2 = 0.07$ ), and environmental domain (p < 0.005,  $\eta 2 = 0.04$ ).

Within the employed subgroup, lower scores in all WHO-QOL-BREF domains were found for those who declared an influence of the disease on their work than in those who did not (physical domain:  $50.0\ vs.\ 64.7,\ p<0.001,\ d=0.89;\ psychological domain: <math>61.5\ vs.\ 71.8,\ p<0.001,\ d=0.61;\ social$  relationships:  $64.6\ vs.\ 72.8,\ p=0.007,\ d=0.38;\ and\ environmental\ domain: <math>62.8\ vs.\ 72.0,\ p<0.001,\ d=0.62).$ 

## Employment and depression

The Beck Depression Inventory results in the study group ranged from 0 to 39 (mean 10.8, SD 8.55). 19.6% of respondents were classified as having mild depression, and 25.6% as having moderate or severe depression (Tab. 3).

**Table 3.** Results of Beck Depression Inventory (BDI) in study group of MS patients

Results of BDI (pts)		Number of cases	%
No depression	≤ 9	125	50.00
Mild depression	(9–5)	49	19.60
Moderate depression	(15–23)	45	18.00
Severe depression	> 23	19	7.60
Incomplete data		12	4.00

Unemployed patients had higher mean BDI scores than employed ones (15.4 vs. 9.05, p < 0.001,  $\eta 2 = 0.09$ ), and the patients who declared the disease's influence on their work had higher scores than those who did not (13.0 vs. 7.53, p < 0.001, d = -0.66).

#### Discussion

More than 70% of respondents to our survey were employed, which is a surprisingly high rate. However, the participants were recruited from regular hospital-based settings in the major cities of two regions. Employment rates in regional MS populations obtained in similar European studies have ranged from 40-80% [7, 14-17]. Data from large multicentre MS cohorts show employment rates at ca. 40% in the USA [18, 19] and over 60% in Europe [3, 20]. In a recent study based on MS registers from Poland, Germany, Sweden and the UK [21], lower employment chances were reported for Polish patients compared to the others. Inequalities and differences across countries have to be taken into account, including legal aspects, welfare benefits, social support programmes, as well as gender differences and the cultural background associated with work participation [16, 20-22]. Furthermore, the lower employment rates seen in older studies indicate recent progress in the management of MS, which allows the impact of the disease upon patients' functioning to be diminished, and also the development of socio-occupational issues with better integration of disabled people [20].

The relatively young age and high education level in the study group may be assumed to have contributed to the high employment rate [14, 19, 23]. As many as 60% of the study group reported having non-manual jobs. Although the type of job seems less relevant to the employment of MS patients than does the level of education [16], with increasing disease duration such patients tend to be employed in non-manual jobs, thus reducing the risk of losing their job [24]. Interestingly, in a Swedish MS cohort [8], most transitions of employment status were observed shortly after the diagnosis. This was supposedly due to the arrangements of the country's welfare system. In longitudinal observation of these newly diagnosed patients, there was also a trend to re-enter the labour market after ca. 4 years of follow-up, which can be attributed to young adults having completed their education and undertaking their first job [8]. Thus, relationships between MS subjects' vocational status and level of education should be considered in multiple aspects.

According to the responses from our study group, the disease not only contributed to the loss of a job or finding a new one, it also infrequently forced a change of employer, or the type of work. The main problems within the workplace environment perceived by MS patients include transport/mobility issues, architectural barriers, and temperature [2, 3]. These obstacles can often be controlled and adapted to the needs of employees, but awareness and the accessibility of the necessary

tools is often insufficient [19, 20]. Anticipated discrimination may also prevent people with MS from disclosing their disease in the workplace. However, disclosure of an MS diagnosis often turns out to be helpful in maintaining employment and accessing adequate support [9, 15, 25]. Psychosocial well-being (including self-confidence and self-efficacy) has been shown to affect substantially work productivity, and this association has been found to be even stronger for those who disclosed MS diagnosis at their workplace [26].

Around 70% of the employed respondents to our survey had disclosed their disease to an employer and/or co-workers, and half of them had indeed been provided with some amenities. These findings indicate the need to develop effective communication in this field, based on an awareness of disease specificity and psychological work-related issues [26].

Workplace-related factors are considered less relevant for vocational activity than are the consequences of the disease [9]. Unemployed MS subjects in the study group had a longer duration of disease and a higher disability level. Both factors have been considered as important and independent predictors of employment [5, 16, 25, 27, 28]. Patients with progressive types of MS are usually regarded as less likely to participate in work than those with relapsing-remitting course [5, 7, 16, 19, 24]. The vast majority of our MS subjects had RRMS, so a comparison of vocational issues between particular disease types was not possible.

Some authors [19, 25] have claimed that ineffective management of particular MS-related symptoms has a more relevant impact upon work than general disability measures. Impairment of mobility, hand dexterity, vision, balance and bladder function have indeed been considered to have a substantial impact upon work performance [3, 9, 17, 19, 29]. Our findings have shown more frequent complaints of ambulation problems, disturbed balance, pain and bladder dysfunction among those subjects who perceived an influence of the disease upon their professional activity. These symptoms belonged to those most frequently reported in the whole study group.

However, other leading complaints — fatigue and visual deficit — showed no significant relationship with the perception of MS burden at work. Fatigue and cognitive decline have been highlighted as relevant predictors of reduction in working hours, limitations to the work schedule, and earlier retirement [2, 3, 5, 7, 15, 16, 28]. The complex links between vocational status, fatigue and cognition can create what is known as a 'vicious circle' [4, 29]. This also concerns mental health issues (e.g. anxiety and depression), which either independently influence vocational activities or add to the burden of MS-related disability; but may also develop due to loss of work. Some studies [14] have reported more depressive symptoms in early retired or unemployed MS patients, while others dispute such a relationship [5]. In our study group, unemployed persons and those who observed a negative impact of MS upon their work scored higher on BDI.

Similar observations emerged from the assessment of WHOQOL-BREF results in our MS group. There is consistent evidence that work participation by MS subjects significantly affects various aspects of their quality of life. Unemployed or early retired patients score lower in general or MS-dedicated QoL scales [2, 5]. The i mpact of work-related issues upon quality of life has been suggested by some authors [15] as being independent of MS duration and degree of disability. Although no such multidimensional analysis was conducted in our study, this would be worth considering in a future investigation. Quality of life may be also associated with the individual situation of the MS patient, e.g. benefits from administrative status in those early retired may outweigh fear of stigmatisation or frustration in the workplace [6, 9].

Overall, evaluation of the patients' perspective on their vocational activity seems necessary if we are to take a holistic approach to disease management and outcome measures [21].

The limitations of this study are mainly associated with selection bias. The p articipants represented hospital-based centres from two regions, so the findings cannot be generalised for the overall Polish MS population. Furthermore, the vast majority of patients had a relapsing-remitting course of MS and relatively mild disability, factors which probably affected the employment rate and the distribution of responses. However, findings from the study group seem relevant for MS subjects with potential job productivity and may provide a better insight into relationships between MS and work-related aspects.

Today, these issues deserve special attention in view of the impact of the SARS-CoV-2 pandemic. Work-related problems due to lockdown significantly contributed to distress in MS patients [30–32], and long-term pandemic consequences in this field are likely to affect their psychosocial condition [31].

Thus these problems need to be addressed with a dequate systemic support.

# Clinical implications/future directions

The clinical symptoms of MS and the associated cumulative disability have a significantly adverse impact upon work-related aspects, something which should be considered among the outcomes of the disease. Unemployment and the perceived influence of this disease on vocational activity are associated with a higher frequency of depression and a lower quality of life in MS patients.

#### Conflicts of interest: None.

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