



# Occupational and Individual Factors Associated with Return to Work in Workers with Multiple Sclerosis

## *Multipl Sklerozlu İşçilerde İşe Dönüş ile İlişkili Mesleki ve Bireysel Faktörler*

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### Abstract

**Objective:** Multiple sclerosis (MS) is a chronic disease of the central nervous system that is usually diagnosed at the working-age (20-45 years) and can negatively affect patients' job performance and ability in work. The purpose of this study was to investigate occupational, individual, and disease-related factors in the return to work in patients with MS.

**Materials and Methods:** This study was performed on all patients with clinically definite MS according to the McDonald criteria who were referred to a neurology clinic from September 2019 to April 2020. The Health and Safety Executive Questionnaire and Multidimensional Fatigue Inventory Questionnaire were used to assess job stress and fatigue level. Level of disability was assessed in patients through the validated version of the Expanded Disability Status Scale (EDSS). Based on the patients' return to work status, individuals were divided into two groups: the patients who returned to work (full time, part-time) and who did not return to work. Then, these two groups were compared in terms of occupational, individual, and disease-related factors.

**Results:** Of 191 patients with MS, 127 (64%) returned to work after one year of diagnosis. The rate of returning to work was higher among younger patients, males and patients with the relapsing-remitting MS. Physical jobs, moderate level of neurological disability (EDSS >3) and severe fatigue were independently associated with unemployment.

**Conclusion:** Findings of our study showed that older age, female gender, having a physical job, neurological disability, and severe fatigue were associated with no return to work in MS patients. Due to the high prevalence of MS in young people at working age, facilitating employment, adjusting factors related to the work environment, and support of colleagues and supervisors can play an important role in reducing stress and improving the general condition of the disease in these patients.

**Keywords:** Central nervous system, fatigue, multiple sclerosis, return to work, worker

### Öz

**Amaç:** Multipl skleroz (MS), genellikle çalışma çağıında (20-45 yaş) teşhis edilen ve hastaların iş performanslarını ve çalışma becerilerini olumsuz etkileyebilen merkezi sinir sisteminin kronik bir hastalığıdır. Bu çalışmanın amacı, MS'li hastalarda işe dönüşte mesleki, bireysel ve hastalıkla ilgili faktörleri araştırmaktır.

**Gereç ve Yöntem:** Bu çalışma, Eylül 2019'dan Nisan 2020'ye kadar bir nöroloji kliniğine sevk edilen McDonald kriterlerine göre klinik olarak kesin MS'li hastalar üzerinde gerçekleştirildi. Sağlık ve Güvenlik Yöneticisi anketi ve Çok Boyutlu Yorgunluk Envanteri anketi iş stresi ve yorgunluk düzeyini değerlendirmek için kullanıldı. Engellilik düzeyi, Genişletilmiş Sakatlık Durum Ölçeği'nin (EDSS) doğrulanmış versiyonu aracılığıyla hastalarda değerlendirildi. Hastaların işe dönüş durumuna göre bireyler işe dönen (tam zamanlı, yarı zamanlı) ve işe dönmeyen hastalar olarak iki gruba ayrıldı. Daha sonra bu iki grup mesleki, bireysel ve hastalıkla ilgili faktörler açısından karşılaştırıldı.

**Bulgular:** MS'li 191 hastadan 127'si (%64) tanı konulduktan bir yıl sonra işine döndü. İşe dönüş oranı genç hastalarda, erkeklerde ve relaps ve remisyonlarla seyreden MS'li hastalarda daha yüksekti. Fiziksel işler, orta düzeyde nörolojik özürüllük (EDSS >3) ve şiddetli yorgunluk bağımsız olarak işsizlikle ilişkilendirildi.

**Sonuç:** Çalışmamızın bulguları, ileri yaş, kadın cinsiyet, fiziksel bir işe sahip olma, nörolojik dizabilite ve şiddetli yorgunluğun MS'li hastalarda işe geri dönmeye ile ilişkili olduğunu göstermiştir. Çalışma çağıındaki gençlerde MS prevalansının yüksek olması nedeniyle, istihdamı kolaylaştırıcı çalışma ortamına ilişkin faktörlerin ayarlanması, meslektaşların ve yöneticilerin desteği, bu hastalarda stresin azaltılmasında ve hastalığın genel durumunun iyileştirilmesinde önemli rol oynayabilir.

**Anahtar Kelimeler:** Merkezi sinir sistemi, yorgunluk, multipl skleroz, işe dönüş, işçi

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## Introduction

Multiple sclerosis (MS) is a common chronic disease of the central nervous system presenting with a variety of neurological, cognitive, and psychological symptoms that may remit, progress, or relapse. This disease is usually diagnosed at the working-age (20-45 years) and can negatively affect one's job performance and working ability (1). Studies have shown that unemployment is a common problem in individuals with MS with a rate between 22% and 80% and has a significant socioeconomic burden (2), and compared to chronic illnesses such as arthritis, type 2 diabetes, or depression, these patients have high levels of unemployment (part-time to full-time) and lower incomes (3,4,5,6). A cohort study demonstrated that, after approximately 2.5 years of diagnosis, 22% of those previously employed patients became unemployed (2). A large-scale study in 2012 showed that the unemployment rate in patients with MS was affected up to 8 years before diagnosis compared to the control group and steadily decreased after confirmation of the diagnosis (5).

Work and employment in patients with MS lead to a high level of quality of life, less welfare dependence, and better clinical and disease management (7,8,9,10). Several studies have been conducted to investigate the causes of unemployment in these patients. A study in 2011 found that disease duration, course type, age, years of education, sex, and general disability were associated with unemployment in these patients (11,12,13). Although the most important cause of unemployment in these patients is the severity of the disease and their disability, there are other reasons for their unemployment (14,15,16,17). Some studies have shown that fatigue (16,18), depression (11,13), motor difficulties (6), cognitive problem (19,20) and memory impairment (13,21,22) can also contribute to unemployment.

In a systematic review conducted in 2018, the role of psychological factors in return to work of these patients has been discussed and it has been found that psychological factors affect the quality of life of these patients and their jobs (23). In most of the studies that have been done in the field of return to work in these patients, only the demographic (e.g. female gender and older age) and disease related factors (progressive disease course and neurocognitive symptoms) have been investigated, and the job type and workplace conditions are not considered (6,24,25). Therefore, due to the importance of employment in patients with MS and limited studies in this field, this study investigated the effects of occupational, individual and disease-related factors on return to work in patients with MS.

## Materials and Methods

The present study is a descriptive-analytical study performed on 212 patients with clinically definite MS according to the McDonald criteria who were referred to a MS clinic from September 2019 to April 2020 (26). Among these patients, those who were under 18 years old, who were over 65 years old (n=9) and who were unemployed at the time of diagnosis (n=12) were excluded from the study. Written informed consent was obtained from each participant before study entry and the protocol was reviewed and approved by the Iran University of Medical Sciences Ethics Committee (protocol no: IR.IUMS.FMD.REC.1397.201, date: 20.11.2018).

Study participants were interviewed in person. The first part of the interview included general information such as age, gender, education level, marital status, smoking (or passive smoking) and history of underlying diseases.

The second part of the interview included occupational information such as job title, work experience, employment status and whether the patient had a working spouse. In this study, patients were classified into two groups according to their job type as physical and non-physical (27). We used the Health and Safety Executive (HSE) questionnaire to assess patients' job stress. The HSE questionnaire has 35 questions. This questionnaire is related to seven main job stressors. The questions are categorized into seven areas of stress: demands, control, managerial support, peer support, relationships, roles, and change. The ratings are on a five-point Likert scale (never, rarely, sometimes, often, and always). The lower the score, the higher the stress level. The validity and reliability of the questionnaire in Persian were confirmed (28,29).

Data including disease duration and age at disease onset, received disease-modifying treatment, and self-reported ratings of current symptoms including pain, fatigue, problems with memory and thinking, bladder and bowel dysfunction (using a five-point Likert scale ranging from 0 "not at all a problem" to 5 "very much a problem") were gathered (30). The Level of disability was assessed in patients through the validated version of the Expanded Disability Status Scale (EDSS) (31).

In this study, we used the Multidimensional Fatigue Inventory (MFI) questionnaire to assess fatigue in patients. This questionnaire was first developed by Mr. Smith in 1996 and could be applied to both patients and healthy individuals. This tool contains 20 questions and is scored on a Likert scale and has 5 subscales including general fatigue, physical fatigue, decreased activity, decreased motivation, and mental fatigue (32). Finally, patients' return to work status was inquired by a question: "Have you returned to work after being diagnosed with the disease?" If the answer was "yes", it was asked "How long after the diagnosis did you return to work?" Based on the answer given, individuals were divided into two groups: patients who returned to work (full time, part-time) and who did not return to work. Then, these two groups were compared in terms of occupational, individual, and disease-related factors.

## Statistical Analysis

The study data were analyzed by Statistical Package for the Social Sciences (version 24). For quantitative data, mean and standard deviation were used. For qualitative data, frequency and percentage were used. For statistical analysis of quantitative and qualitative data, independent sample t-test and chi-square test were used, respectively. All statistical tests resulting with a p value less than 0.05 were considered statistically significant.

## Results

The present study was performed on 191 patients referred to the MS clinic. The majority of participants (58.64%) had relapsing-remitting MS (RRMS) and the mean EDSS score was  $3.28 \pm 1.3$  with a range of 1.5 to 8. There was no difference in terms of receiving disease modifying treatment between the two groups. Furthermore, no drug side effects leading to disability or non-returning to work were observed in the patients.

The mean age was 34.2±7.5 years with a range of 24 to 55 and 62.83% were female.

The mean work experience was 9.1±5.6 years with a range of 1 to 20 years and 51.31% had non-physical work. In terms of returning to work, 127 (64%) patients returned to work and 64 (36%) did not return to work after one year of diagnosis. Among those who returned to work, 87 (68%) had full-time jobs, 25 (20%) had part-time jobs, and 15 (12%) changed their jobs. Among those who did not return to work, 23 (36%) were fired, 25 (39%) were unable to work, and 16 (25%) were supported by their families. The demographic and work-related characteristics of the participants are shown in Table 1.

**Return to Work and Demographic Variables**

Patients who returned to work were younger (p<0.001) and the majority of them were male (p<0.05) and had a higher level of education (p<0.05). There was no statistically significant relationship between marital status, number of children, and smoking status between the two groups (Table 2).

**Return to Work and Work Related Variables**

Patients who did not return to work had a higher percentage of physical jobs than patients who returned to work (66.9% vs. 39.4%, p<0.0). There was a statistically significant relationship between spouse employment and having insurance and non-returning to work (p<0.05) (Table 2).

The average final score of job stress (HSE) in patients who did not return to work was higher than patients who did (3.4 vs. 2.3); but there was no statistically significant difference between the two groups (p≥0.05). In terms of different dimensions of stress including demand, peer support, control, and manager support, there was a statistically significant difference between the two groups (p<0.05). Patients who returned to work, had less job stress (Table 3).

**Return to Work and Disease Severity**

The average EDSS score of patients who did not return to work was higher than those who did (p<0.001). The average MFI total score in patients who did not return to work was higher than those who did (44.7±18.4 vs. 60.1±6.8, p<0.001). Also, mean general fatigue (p=0.023) and mental fatigue (p<0.001) were significantly higher, and motivation score (p=0.025) was significantly lower in patients who did not return to work (Tables 2 and 3). All subjects with fatigue were treated with amantadine and there was no difference in the treatment of fatigue between the two groups.

**Factors Influencing Employment**

There was a statistically significant relationship between not returning to work and EDSS score >3 [p<0.001, odds ratio (OR): 9.7], MFI total score >40 (p<0.001, OR: 4.37), HSE score <2.5 (p=0.05, OR=1.12), and progressive type of disease (p<0.001 OR: 3.39).

Multivariate logistic regression analysis revealed that moderate level of neurological disability (EDSS score >3), physical jobs, MFI total score >40, and older age were independently associated with unemployment (Table 4).

**Discussion**

The present study was performed on 191 employed patients with MS to evaluate their return to work status after diagnosis

**Table 1. Demographic, occupational and disease-related characteristics of the participants**

Variables		Mean ± SD/ number (%)
Age (year)		34.2±7.5
Work experience (year)		9.1±5.6
Gender	Female	120 (62.8)
	Male	71 (37.1)
Marital status	Married	94 (49.21)
	Single	97 (50.7)
Spouse employment status	Yes	25 (27)
	No	69 (73)
Smoking	Yes	20 (10.4)
	No	171 (89.5)
Education	High school	21 (11)
	Associate degree and diploma	39 (20.4)
	Bachelor	79 (41.4)
	Master's degree	40 (20.9)
	Doctorate	12 (6.3)
Job category	Physical	93 (48.6)
	Non-physical	98 (51.3)
Duration of diagnosis (year)		5.7±4.2
Expanded Disability Status Scale score		3.28±1.3
Course of the disease	Relapsing remitting	112 (58.6)
	Secondary progressive	38 (19.9)
	Primary progressive	29 (15.1)
	Progressive relapsing	12 (6.2)
Primary symptoms	Vision problems	92 (48)
	Numbness and tingling	67 (35)
	Mobility problem	50 (26)
	Balance problems	33 (17)
	Fatigue	36 (19)
Current symptoms	Vision problems	30 (15)
	Numbness and tingling	31 (16)
	Mobility problem	38 (20)
	Balance problems	69 (36)
	Fatigue	59 (31)
	Urinary incontinence	14 (7)
Foot drop	15 (8)	
Wheel-chair dependency	11 (6)	

SD: Standard deviation

**Table 2.** Return to work status based on demographic, occupational and disease characteristics

Variables	Return to work		p value	OR (95% CI)
	Yes Mean ± SD	No Mean ± SD		
Age (year)	31.4±4.6	38.9±8.9	<0.001	-
Years of education	15.96±2.1	13.18±3.4	<0.001	-
Work experience (year)	9.4±6.2	8.5±4.3	0.278	-
Duration of diagnosis (year)	5.4±4.2	6.2±3.9	0.208	-
Expanded Disability Status Scale score	2.8±1.2	4.1±1.18	<0.001	-
	Number (%)			
Gender (male)	48 (37.7)	22 (34.4)	0.041	1.43 (1.23-1.88)
Marital status (married)	41 (52)	28 (43.7)	0.645	1.15 (0.63-2.10)
Spouse employment (no)	77 (60.7)	45 (70.4)	0.031	1.10 (1.05-1.21)
Smoking (yes)	16 (12.6)	4 (6.3)	0.176	0.46 (0.14-1.44)
Job category (non-physical)	77 (60.6)	21 (33.1)	0.002	1.80 (1.95-3.43)
Insurance (no)	37 (29)	37 (57.8)	0.027	1.09 (1.01-1.67)
Vision problems (yes)	60 (47.2)	32 (50)	0.304	1.22 (0.61-2.21)
Numbness and tingling (yes)	42 (33)	25 (39.1)	0.425	1.33 (0.70-2.48)
Mobility problem (yes)	25 (19.6)	25 (39.1)	0.014	1.33 (1.21-1.82)
Balance problems (yes)	18 (14.1)	15 (23.5)	0.022	1.34 (1.10-1.81)
Relapsing remitting MS	87 (68.5)	25 (39.1)	<0.001	3.39 (1.81-6.34)
Primary progressive MS	40 (31.5)	39 (60.9)	<0.001	2.13 (1.15-3.94)

SD: Standard deviation, MS: Multiple sclerosis, OR: Odds ratio, CI: Confidence interval

**Table 3.** Comparison of return to work status with fatigue and job stress scores

	Return to work		p value
	Yes Mean ± SD	No Mean ± SD	
Total MFI	44.7±18.4	60.1±6.8	<0.001
General fatigue	10.9±1.2	11.5±1.6	0.023
Physical fatigue	12.3±2.2	12.4±2.09	0.733
Decreased activity	11.4±2.1	11.6±2.1	0.575
Decreased motivation	12.1±1.8	16.05±1.2	0.025
Mental fatigue	12.6±2.04	13.6±1.5	0.001
Total HSE	3.4±2.7	3.2±2.1	0.260
Demand	3.04±1.5	2.8±3.32	0.035
Control	3.7±5.6	3.5±6.5	0.044
Peer support	3.16±1.7	2.92±3.2	0.028
Manager support	3.5±5.1	3.08±2.7	<0.001
Relationship	3.07±1.7	2.98±4.1	0.401
Role	3.58±1.2	3.74±2.1	0.060
Change	3.07±4.3	3.5±4.7	0.895

MFI: Multidimensional Fatigue Inventory, HSE: Health and Safety Executive, SD: Standard deviation

**Table 4.** Regression analysis of return to work status based on demographic, occupational and disease-related factors

	p value	OR	(95% CI)
Age	0.050	1.29	1.13-1.49
Gender (male)	0.042	0.12	0.11-1.14
Education	0.567	0.92	0.74-1.39
Spouse employment (no)	0.031	2.21	2.94-3.12
Job category (physical)	0.002	2.84	1.85-3.17
Relapsing-remitting course	0.011	1.24	1.14-1.35
EDSS >3	<0.001	3.10	2.21-5.25
MFI total >40	0.03	2.12	1.78-3.16
HSE <2.5	0.06	0.81	0.11-1.27

MFI: Multidimensional Fatigue Inventory, HSE: Health and Safety Executive, EDSS: Expanded Disability Status Scale, OR: Odds ratio, CI: Confidence interval

of the disease. To our knowledge, this is the first report about demographic, work-related, and clinical factors leading to unemployment in patients with MS. This study showed that demographic factors such as older age at the time of diagnosis and low level of education had a negative influence on return to work. Also, the rate of return to work was higher among male patients but marital status was not significantly associated with return to work status. Some studies found that individual factors such as older age had a negative influence on the employment status (33,34,35). A meta-analysis found that older age and lower

education harmed employment (34). This could be because young people were more motivated and had more life expectancy, and could accept more conditions. Our findings are consistent with the results obtained in other countries (8,33,36,37). The association between low education and non-returning to work may be due to the fact that people with higher education are usually employed in non-physical jobs (which was the case in our study); since MS causes sensory and motor problems, subjects with higher education are more likely to return to work. In addition, higher education gives people more job opportunities and job security.

Among the factors related to work, having a non-physical job and not having health insurance were associated with higher rate of return to work. But, there was no relationship between work experience and the rate of return to work. Studies in this field have shown that unemployment in patients with MS is due to the interaction between disease-related factors and other factors such as supervisor's and co-workers' support, job demands, and physical work environment (38,39).

From different aspects of job stress, patients who had more peer support and manager support had a high rate of return to work, and patients with less job stress in terms of demand-control had high rate of return to work. The presence of job stress along with other factors related to the disease can harm patients' return to work. Based on studies conducted so far, it seems that the relationship between stress in the workplace and employment rate is a two-way relationship. People receiving less support from their co-workers and supervisors are less likely to return to work because in stressful work environments, people worry about losing the job, they are not able to perform the assigned job tasks, and the disease continues to progress (40,41,42).

In terms of disease-related factors, mental and general fatigue had a negative effect on returning to work and high level of fatigue doubled the risk of unemployment. In the study by Koziarska et al. (33), severe fatigue was associated with non-returning to work in patients with MS, which was similar to the results of our study. Given that MS is a chronic and progressive disease and fatigue is one of the most important symptoms of the disease, patients with higher levels of fatigue are more likely to be disabled and therefore, return to work will be more difficult in these patients (43).

In our study, it was found that the rate of disability (EDSS score >3) was the most important factor in not returning to work and increased the possibility of unemployment by three times. The type of disease was also effective on returning to work, and participants with the RRMS were more likely to return to work and those with the PPMS were less likely to return to work. There was no statistically significant relationship between the duration of MS and no return to work.

Our study had several strengths compared to studies on the employment of patients with MS. All of the participants in our study were employed at the time of diagnosis, and the effect of MS on employment and return to work was assessed. In other studies, individuals were assessed regardless of their employment status at the time of diagnosis. In this study, in addition to individual factors, we assessed occupational and disease-related factors and their impact on return to work, while in other studies, one or two of these factors were assessed.

### Study Limitations

One of the limitations of our study was that due to the cross-sectional design of the study, it was not possible to investigate the

predictive effect of various factors on returning to work status. In addition, in this study, occupations were classified into only two groups as physical and non-physical, whereas using more details about the job tasks of the participants would have lead to more accurate results.

### Conclusion

Findings of our study showed that among demographic factors, older age, female gender, spouse unemployment; among work-related factors, having a physical job; and among disease-related factors, EDSS score >3, and severe fatigue were associated with not-returning to work in patients with MS. Given the high prevalence of MS and the fact that this disease is more common in young people at working age, facilitating employment, modifying factors related to the work environment, and support of colleagues and supervisors in the workplace can play an important role in reducing stress and improving the general condition of the disease in these patients.

### Ethics

**Ethics Committee Approval:** The study was approved by the Iran University of Medical Sciences Ethics Committee (protocol no: IR.IUMS.FMD.REC.1397.201, date: 20.11.2018).

**Informed Consent:** Written informed consent was obtained from each participant before study entry.

**Peer-review:** Externally peer-reviewed.

### Authorship Contributions

Surgical and Medical Practices: M.H.H., Concept: E.K-M., M.H.H., Design: E.K-M., Data Collection or Processing: R.S., S.K., Analysis or Interpretation: M.H., S.M., Literature Search: M.H., E.K-M., M.H.H., Writing: M.H., E.K-M.

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