

Employment-associated factors in multiple sclerosis: Results of a cross-sectional study in Germany

Christiane Sterz, David Ellenberger, Heike Meißner, Tim Friede, Peter Flachenecker

ABSTRACT

Aims: Identification of employment-associated factors with regard to patients with multiple sclerosis (PwMS) in Germany: the impact of the working situation on PwMS, the subjective difficulties and problems PwMS may experience at their work place and the reasons for withdrawing from work. **Methods:** 279 PwMS (189 employed (EM), and 90 early retired (ER)) completed a comprehensive questionnaire with standardized instruments: Multiple sclerosis work difficulties questionnaire (MSWDQ) on workplace related problems, Würzburger screening (WüScr) on perceived burden of disease with regard to work. Further general data about employment status, multiple sclerosis disease information including main symptoms and patients adaptations for an optimal working place were collected. Employed PwMS were asked about their challenges at current working place, ER PwMS about their last job and their reasons for stop working. **Results:** Statistically significant factors for employment were disease duration ($p < 0.001$), EDSS ($p < 0.001$) and educational level ($p = 0.0237$). According to MSWDQ, PwMS rated employment as very important, 48% of EM patients

considered not to stop working or to change job completely (58%) and 40% did not plan to reduce work. According to WüScr PwMS were highly burdened by their disease. Perceived burden of work and workplace-related factors contributed to early retirement. Multivariable regression analyses showed the main symptoms associated with workplace difficulties: mobility/walking, pain, mood, balance, cognitive impairment, vision disturbances and fatigue. With regard to maintenance of employment, EM and ER patients requested adaptations of their work place such as better accessibility, flexible working time, less stress and more ergonomically designed elements. **Conclusion:** In order to keep PwMS longer in employment, the results of our study indicate that it is necessary to properly assess MS symptoms and treat them adequately, to optimize their work places, and to raise awareness among employers and colleagues for the special needs of PwMS.

Keywords: Early retirement, Employment, Multiple sclerosis, Symptoms

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INTRODUCTION

Multiple sclerosis (MS) is a chronic neurological disease with various symptoms leading to specific disabilities. It is accompanied by high rates of unemployment and early retirement. Among all chronic diseases, patients with MS (PwMS) show the highest unemployment rates [1], ranging from 70–80% being unemployed within 5–10 years of disease onset [2]. With a typical onset between 20 and 40 years of age [3], MS normally hits young people at the beginning of their adulthood, usually when they plan their life and start or consolidate their professional career [4]. Employment is a major factor for quality of life of PwMS because it gives structure to daily life and may help them to reach and maintain a kind of normality [5]. It ensures ones livelihood, which leads to social esteem and appreciation and thus enhances self-confidence. Despite this positive impact of work on PwMS, international studies show high rates of unemployment and early retirement [4, 6]. While most people are employed at time of diagnosis [7, 8] and 90–96% have a work history [2, 7] nearly half of them leave work and change to early retirement within 15 years of diagnosis [4, 9]. In Europe, rates across countries vary between 33% and 45% [10], and even 36% of PwMS in their most productive life span between 35 to 44 years of age are early retired [3]. This impacts not only on quality of life of PwMS, but also contributes significantly to the overall cost of MS and has thus a huge impact on society as well [10].

Although reasons for unemployment in MS including demographic factors (age, gender, education), disease characteristics (course of MS, disease duration, disability), MS symptoms such as mobility restrictions, depression, fatigue and cognition, and workplace factors have been observed in many countries [4, 6, 9, 11–14], detailed data on the working situation for PwMS in Germany are lacking. In the German MS registry, only 28% of PwMS were fully employed, and 39% were early retired [3], but reasons and associated factors for employment were not known.

Therefore, the aim of this study was the identification of employment-associated factors with regard to MS-patients, in detail: the impact of the working situation on PwMS, the subjective difficulties and problems PwMS may experience at their work place and the reasons for withdrawing from work in a large sample of PwMS in Germany.

PATIENTS AND METHODS

Patients

The study was approved by the Landesärztekammer Baden-Württemberg (Ref. No.: F-2013-016). Eligible

patients were those who (1) were diagnosed with MS according to the McDonald criteria [15], (2) were admitted to inpatient rehabilitation at the Neurological Rehabilitation Centre Quellenhof Bad Wildbad, Germany, between May and November 2013, and (3) gave written informed consent to participate in this study. Out of 483 patients, 279 PwMS were included (189 employed, EM, and 90 early retired, ER). The main reasons for those not included (n=204) were lack of memory about details of their employment situation (n=72), age over 65 years (n=48), newly diagnosed with MS -beginning of rehabilitation immediately after initial diagnosis- (n=30), cognitive impairment (n=17), unwillingness to participate (n=17), never been employed (n=9) and others (n=11).

Methods

Based on the results of a literature search e.g., PubMed and ASP via EBSCOhost with keywords “unemployment”, “employment”, “work ability” and “MS” about the influencing factors on employment of MS patients, a comprehensive questionnaire was developed including standardized elements. Main instruments in particular were the MS work difficulties questionnaire (MSWDQ) [16] and the Würzburger screening (WüScr) for working problems [17] (Table 1).

The MSWDQ is a validated instrument consisting of 50 items which are merged to twelve subscales: mobility/movement difficulties, fatigue, financial security concerns, general cognitive difficulties, work-home-balance duties, low self-esteem, pain/temperature difficulties, non supportive workplace, bladder/bowel difficulties, interpersonal difficulties, prospective memory difficulties, workplace inaccessibility. The MSWDQ shows the unique challenges PwMS may encounter at their work place (current job or last job prior to retirement). The items reflected the subjective perception of PwMS about their working problems’ because the individual perspective may be different from objective difficulties. Possible responses were on a 5-point-Likert scale ranging from 0 (never) to 4 (always). The twelve subscales of the MSWDQ were calculated [16]. Additional questions were asked about how likely it would be to give up work, reduce working hours, or change type of work. These ratings were also measured on a 5-point-scale from 0 (very unlikely) to 4 (very likely). Higher scores indicated a higher level of problems. A German version of the MSWDQ was developed by the authors by using the translation / re-translation method, which was subsequently validated [18].

Employment-related burden was measured by the “Würzburger Screening für berufliche Problemlagen” (WüScr) [17]. The questions dealt with limitation of job performance, influence of workload on health, and burden of employment status by using a 5-point Likert scale, ranging from 1 (not at all) to 5 (very much), with higher scores indicating a higher degree of burden. Additional

questions dealt with appearance and severity of relevant MS symptoms (6-point Likert scale ranging from 0 =no problem at all to 5 =very much a problem). Other questions were about importance and consciousness of employment and requested adaptations for an optimal working place (open ended question and predetermined statements with a 5-point Likert scale: 0=not at all to 4=very much).

Disease-related data were taken from the medical records including neurological disability, rated with the expanded disability status Scale EDSS [19].

The questionnaires for the employment (EM) and early retirement (ER) groups were nearly identical. The only differences were that the EM group was asked about their current work place, and the ER group about the experiences at their last work place and their situation at the time when they stopped working. In addition, ER patients were asked about their reasons for giving up employment by means of two open ended questions dealing with “all reasons” and “the most important reason”.

Statistical analyses

Descriptive statistics include frequencies and percentages for categorical data as well, quartiles for ordinal outcomes and means and standard deviations for metric outcomes. Univariate comparisons between the two groups, EM and ER, were done using chi-square tests, Wilcoxon-Rank-Sum tests or Welch’s t-tests for binary, ordinal and continuous data, respectively.

If symptoms were present, their severity was compared between both groups with a non-parametric alternative to the ANCOVA [20] using propensity scores to adjust for the confounders gender, educational level, as well as age and disease duration at retirement (ER), or current age and disease duration (EM).

Analyses for the association between symptoms and the ordinal subscales of the MSWDQ multivariable (and WüScr) regressions on the ranked data [21] were conducted, with standardized coefficients (beta values) as effect measures. For each MSWDQ subscale a backward selection procedure (based on the significance level) was applied on all 15 symptoms (as independent variables) to reduce the risk of overfitting.

Statistical analyses were conducted with SAS version 9.3 (SAS Institute Inc. Cary, USA) and p-values smaller 5% are considered statistically significant. Due to the exploratory nature of the study, p-values were not adjusted for multiple testing. Power calculations yield a power of over 85% for comparing two groups of sample sizes 90 and 189 patients given an effect size of 0.4 in terms of probabilistic index (probability to observe a more favorable outcome in one group compared to the other) [20].

RESULTS

Demographics and disease related characteristics

The EM group included 189 employed patients (121 females) with mean age (at time of survey) 42.3±9.9, mean disease duration 8.9±7.34 years and median EDSS 3.5 (2.5–5.5). The ER group contained 90 retired PwMS (53 females) with mean age 49.2±7.7, mean disease duration 14.2±7.2 years and median EDSS 6.5 (6.0–7.25). Age, disease duration, EDSS and conversion from relapsing-remitting (RR)-MS to secondary progressive (SP)-MS were significantly higher in the ER group, while educational level was lower. Further details are provided in Table 2.

Employment-related burden and future anticipation of work in employed PwMS

According to the WüScr, employed PwMS were highly burdened by their disease. With regard to all dimensions, 40% were highly burdened (points 4–5), and 50% of EM patients felt still reasonably burdened (points 2–3) by their working conditions. The number of patients who reported not to be burdened at all was quite small (Table 3).

The question on future anticipation of work (according to the MSWDQ) revealed the importance of employment for PwMS. 48% did not want to withdraw from work completely, 40% did not consider to reduce working hours, and 58% refused to change type of work in the future. On the other hand, about 50% were unsure how to deal with their future situation or how to change their working situation (Table 3).

Burden of symptoms, their effects on employment and MSWDQ

The pattern of symptoms (reported by PwMS) displayed a particular ranking, with statistically significant differences between the EM and ER groups even after adjustment for demographic covariates for mean values of vision disturbances, bladder/bowel problems, mood, cognitive impairment such as thinking and memory, temperature difficulties, spasticity and balance (Figure 1).

Within the EM group the twelve subscales of the MSWDQ followed the ranking sequence shown in Figure 2, with statistically significant differences between the two groups for movement/mobility difficulties, workplace inaccessibility, financial security concerns and general cognitive difficulties (Figure 2).

Multivariable analyses between MS-symptoms and MSWDQ revealed that pain, mood, balance difficulties, cognitive impairment and vision disorders, correlated

significantly with various dimensions of the MSWDQ in the EM group. With regard to ER patients pain, mood and cognitive impairment correlated with employment, as well as temperature difficulties and fatigue (Table 4).

To corroborate these results, additional multivariable analyses were performed between MS symptoms and WüScr. In this analysis, pain, mood and cognitive

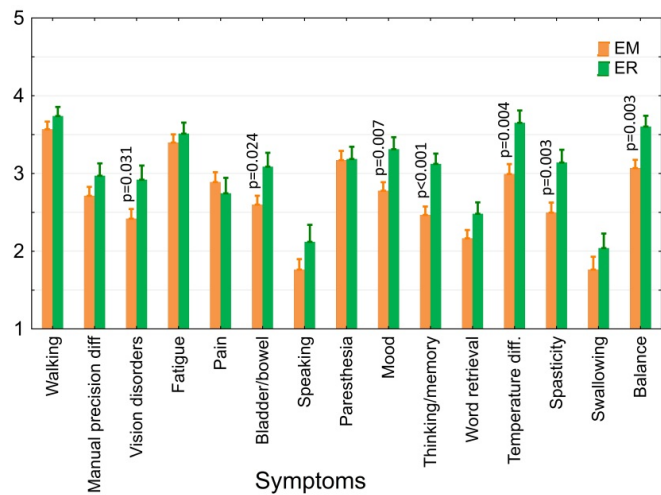


Figure 1: Burden due to symptoms of multiple sclerosis (MS). Burden with regard to employment according to symptoms of MS rated on a 6-point Likert scale (0 = not at all a problem, 5 = very much a problem). Mean-values and standard errors are reported for category 1–5. EM = employed patients; ER = early retired patients. *($p < 0.05$ between EM and ER)

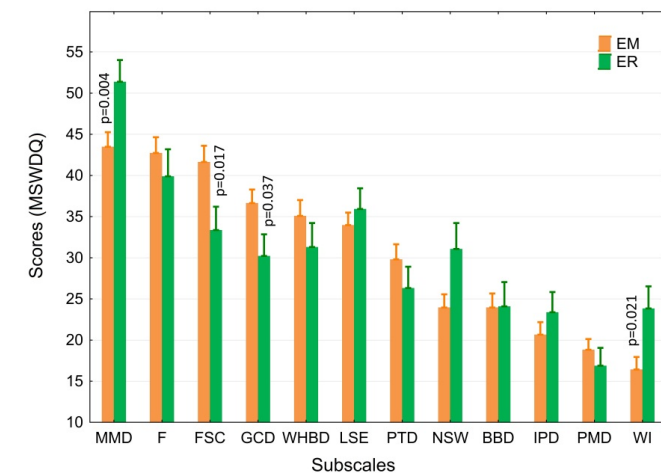


Figure 2: Mean subscale scores and standard errors of the MSWDQ in EM and ER patients. Subscales: movement/mobility difficulties (MMD), fatigue (F), financial security concerns (FSC), general cognitive difficulties (GCD), work/home balance duties (WHBD), low self- esteem (LSE), pain/temperature difficulties (PTD), non-supportive workplace (NSW), bladder/bowel difficulties (BBD), interpersonal difficulties (ID), prospective memory difficulties (PMD), workplace inaccessibility (WI). Subscale scores are computed according to [16] as a percentage by summing up observed item scores and dividing this by the total possible item scores in each subscale and then multiplying this value by 100. *($p < 0.05$ between EM and ER).

difficulties correlated with employment related burden (Table 5). A summary of those symptoms that were associated with workplace difficulties/early retirement in the EM and ER groups according to the different instruments is given in Figure 3.

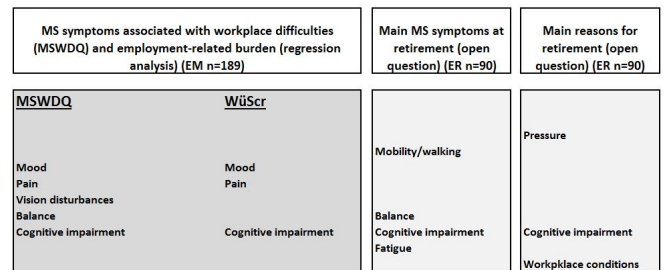


Figure 3: Symptoms associated with workplace difficulties/early retirement.

Reasons for withdrawing from work and measures that could improve working conditions

The most important reasons for withdrawing from work in the ER group according to open ended questions were too much pressure/burden (48%), mobility difficulties (34%), MS symptoms in general (28%), cognitive difficulties (26%), fatigue (16%) and workplace conditions (14%). The most frequent symptoms at the beginning of retirement were movement/mobility difficulties (48.9%), fatigue (33%), balance problems (27%) and cognitive difficulties (26%).

Both groups were asked whether adaptations were requested for an optimal working place. While employed PwMS preferred regular breaks, flexible working time, less time pressure, temperature control and working in a sitting position, early retired PwMS wished that they have had more support from employer and colleagues and more opportunities to work from home. Both groups requested special offers such as having regular therapeutic support or information about legal aspects.

DISCUSSION

Demographics and disease related characteristics

The working pattern in our study reflected the employment characteristics of MS-patients reported in literature: most people were employed at time of diagnosis [7, 8] and did have a work history at all [2]. Out of 483 contacted PwMS only nine patients reported that they had never been employed.

Table 1: Questionnaire structure

Main Elements	Variables studied
MSWDQ	workplace related problems future anticipation of work
WüScr	limitation of job performance burden of employment status influence of workload on health
Employment	importance and consciousness
Demographics	age, gender, education
Disease information	disease duration, disease course, age of onset
EDSS	neurological disability status
MS Symptoms	occurrence and severity of MS symptoms (list)
Workplace adaptations	requested adaptations for optimal working place (list)
Only for ER patients	reasons for giving up employment

Abbreviations: MSWDQ: Multiple sclerosis work difficulties questionnaire, WüScr: Würzburger screening für berufliche Problemlagen, EDSS: Expanded disability status scale

Table 2: Demographic data and disease related characteristics in employed (EM) and early retired (ER) PwMS

	Employed (n = 189)	Early retired (n = 90)	p-value
Gender (male/female)	68/121 (36%/64%)	37/53 (41%/59%)	0.4081
Age	42.3 ±9.9	49.2 ±7.7	<.0001
Age of onset	29.5 ±8.4	30.0 ±9.2	0.6654
EDSS (Median)	3.5 (2.5-5.5)	6.5 (6.0-7.25)	<.0001
Disease duration	8.9 ±7.3	14.2 ±7.2	<.0001
Disease course	RR 105 (61.8%) sCP 56 (32.9%) pCP 9 (5.3%)	18 (21.7%) 56 (67.5%) 9 (10.8%)	<.0011
Education			0.0237
Elementary School	93 (49.2%)	59 (65.6%)	
High School	20 (15.3%)	9 (10.0%)	
College	40 (21.2%)	14 (15.6%)	
University	26 (13.8%)	8 (8.9%)	

Abbreviations: RR: relapsing-remitting MS; sCP: secondary progressive MS; pCP: primary progressive MS; EDSS: Expanded disability status scale.

Table 3: Employment-related burden and future anticipation of work in employed PwMS

Employment-related burden (according to WüScr)			
	Limitation of job performance (n=188)	Influence of work load on health (n=188)	Burden of employment status (n=188)
Not at all (1)	7 (3.7%)	22 (11.7%)	16 (8.5%)
Rarely/somewhat (2+3)	107 (57.0%)	94 (48.8%)	94 (50.0%)
Fairly/very (4+5)	74 (39.4%)	72 (38.3%)	78 (41.5%)
Future anticipation of work (according to MSWDQ)			
	Withdraw from Work (n=189)	Reduce work hours (n=188)	Change work (n=189)
No (0+1)	101 (48.2%)	75 (39.7%)	110 (58.2%)
Unsure (2)	58 (30.7%)	41 (21.8%)	36 (19.1%)
Yes (3+4)	40 (21.2%)	72 (38.3%)	43 (22.7%)

Abbreviations: WüScr: Würzburger Screening für berufliche Problemlagen, MSWDQ: Multiple sclerosis work difficulties questionnaire

Table 4: Symptoms of MS affecting employment (MSWDQ)

	EM (n=146)			ER (n=75)		
	R ²	beta	p	R ²	beta	p
MSWDQ	0.47			0.43		
Pain		0.34511	<.0001		0.25381	0.009
Mood		0.24876	0.0003		0.20111	0.0367
Balance		0.19165	0.0037		NS	NS
Cognitive impairment (thinking /memory)		0.15524	0.0224		NS	NS
Cognitive impairment (word retrieval difficulties)		NS		NS	0.31409	0.0014
Vision disorders		0.17226	0.012		NS	NS
Temperature		NS	NS		0.28369	0.0023
Fatigue		NS	NS		0.22745	0.018

Given are standardized multiple regression coefficients (beta) and related p-values (p) on the influence of various symptoms (as reported by PwMS) on the MSWDQ. For the overall goodness of fit the adjusted R² is calculated.

Abbreviations: EM=employed PwMS; ER= early retired PwMS; MSWDQ: Multiple sclerosis work difficulties questionnaire

Table 5: Symptoms of MS affecting employment (WüScr)

		EM (n= 188)	
	R ²	beta	p
Limitation of job performance	0.22		
Pain		0.2367	0.0014
Mood		0.21445	0.0027
Cognitive impairment (Word retrieval difficulties)		0.14143	0.0438
Influence of workload on health	0.19		
Pain		0.2451	0.0005
Mood		0.20948	0.0049
Cognitive impairment (thinking /memory)		0.14975	0.0355
Burden of employment status	0.15		
Pain		0.1966	0.0074
Mood		0.21267	0.0035
Temperature		0.16113	0.0305

Given are standardized multiple regression coefficients (beta) and related p-values (p) on the influence of various symptoms (as reported by PwMS) on employment related burden (WüScr). For the overall goodness of fit the adjusted R² is calculated.

Abbreviations: EM=employed PwMS; WüScr: Würzburger screening für berufliche problemlagen

In our study, we explored various variables interacting with employment status of MS patients. Fundamentally, we identified shorter disease duration as associated factor for employment status, which is in line with the observations of others [8, 22]. Educational level was another important factor for employment status which is also widely confirmed in literature [9, 11, 3, 23–25]. Thirdly, we found that disability (as assessed by the EDSS which is heavily weighted towards mobility and walking) is another significant factor, which is in line with other findings [9, 26, 27]. However, the level of (physical) disability cannot fully explain the levels of unemployment. While a correlation between the rates of unemployment and the physical disease severity is often reported, a considerably high proportion (15%) of retired PwMS in a German study have still unlimited walking capacity (EDSS ≤ 3,5) [3]. This means that other factors besides disability level must influence PwMS to stop working.

In this regard, besides mobility restrictions and balance problems, we found several other disease-related factors contributing to unemployment such as pain, mood, cognitive impairment, vision disorders and fatigue, which need to be properly taken into account when one attempts to evaluate the work ability of PwMS.

Employment-related burden and future anticipation of work in employed PwMS

Another aim of our study was to focus on the subjective perception of work. Albeit PwMS were highly burdened

by their disease employment is very important for them. According to the Würzburg screening inventory, employed PwMS perceived a high burden due to the manifestation of MS while working. Strong correlations between symptoms and employment related burden (WüScr) were found showing that mood, pain and cognitive impairment were responsible for strain around working situation.

Other findings from our MSWDQ analysis of the future anticipation of work showed that employment is very important to PwMS. Approximately, half of EM patients did not plan to withdraw, reduce or change their job. But on the other hand, the other half were unsure how to deal with their work in the future or just planned to withdraw from work, reduce work hours or change their job. These findings reflect those of a study in the USA, where 64% of the participants believed to be employed one year later, 23% responded a chance of 50/50 and 14% saw themselves not to be employed [28].

With regard to the work place situation, the results from open ended questions answered by the ER group (reasons responsible for leaving employment) confirmed our findings: The main reason was too much “pressure/burden”. Permanent chronic stress on work is supposed to increase odds of disability [29]. Moreover, Smith observed higher negative mood-ratings amongst employed PwMS which possibly reflects a higher stress level while working [30]. Thus, perceived work pressure seems to be a decisive factor for withdrawing from work which is not primarily disease related but specifically results from working environment and job demands.

Burden of symptoms, their effects on employment and MSWDQ

The strength of this study was that we looked at MS symptoms in three different ways.

First, we described the symptoms associated with work inability in general. This general description of various MS symptoms did not disclose considerable differences between the symptoms, so it hardly allows drawing conclusions on unemployment situation.

Second, we used the MSWDQ to reveal symptom-related factors. With this instrument mobility/movement, fatigue and cognitive difficulties were identified as most important symptoms. This is in line with the findings of an Australian study, where the most common reasons related to symptoms to give up employment were fatigue (70%), physical problems (43%), difficulty with memory or thinking (37%) and heat sensitivity (30%) [14]. Thus, the recently created MSWDQ [16] represents an important instrument to explore the factors determining working environment and employment-situation of MS patients and should be used in future studies dealing with employment of PwMS.

Third, we applied multiple regressions on MS symptoms and respective workplace situation from the MSWDQ. With this method, we obtained a meaningful explanation which symptoms are relevant for unemployment. The “Top 5” MS symptoms of EM (as identified with this instrument) were pain, mood, balance, cognitive impairment and vision disturbances, which correlate significantly with various symptomatic problem dimensions from the MSWDQ. Additionally, we found fatigue as a contributing factor for ER group.

With this approach, we have three lines of evidence for the impact of MS symptoms on employment status indicating the robustness of our findings. Although many of the symptoms that we have identified as relevant for the employment situation of PwMS can be found in literature as well [9, 12, 14], this is the first study investigating in detail the relationship between symptoms and work ability with appropriate statistical methods.

Measures that could improve working conditions

Our findings concerning the requested adaptations for an optimal work place confirmed the demand of simple but early support for working environment for PwMS [27, 31–32]. Both groups requested rather unspectacular, but nevertheless helpful changes. Apart from working conditions which are tailored towards the particular needs of PwMS such as flexible working time and regular breaks, working accessibility was another important factor in our study which is in line from the findings of the MSIF survey [6, 14]. Additionally, regular offers of therapeutic and medical measures were requested. These modifications were also recommended by others [1, 31].

More information about legal rights is also demanded in previous studies [1, 31, 33, 34].

Early interventions with regard to work ability may be particularly important given the fact that a high percentage of PwMS change to retirement within the first years after diagnosis [3, 13]. A considerable proportion of our patients was “unsure” about their future employment situation; this group underline the necessity of early and regular assessment and interventions on the current job to influence working situation and may benefit most from programs aimed at keeping PwMS in the work process as long as possible. The need for a systematic management of MS related burden and optimal workplace adjustments for PwMS is obvious. In this regard, the approach of the Swiss Multiple Sclerosis Society of case management procedure seems to be very effective. It involves all relevant partners coordinated by a case manager, applies a result oriented strategy to adjust work environment and content for the employee with MS and optimizes their economic contribution in the workplace [35].

There were some limitations of our study. The length of the retirement period was not restricted in our retrospective evaluation. This means that some people may have difficulties to remember all details leading exactly to retirement. However, patients normally articulated this fact and were excluded if this was the case. Moreover, our data confirmed that there seems to be no influence of retirement period on the data as confirmed by the statistical analysis on duration of retirement and job importance/ job satisfaction. Furthermore, retired PwMS were sometimes unable to fill out their questionnaire by themselves because of problems with fine motor skills. We tried to overcome this issue by offering help which may introduce bias. The ER group was significantly older and had greater physical disability than the EM group. Furthermore, only patients admitted to inpatient rehabilitation were included which may limit the generalizability of our results.

CONCLUSION

The results of our study indicate that maintenance of employment is decisive for patients with multiple sclerosis (PwMS). The MSWDQ helps to identify the subjective difficulties PwMS may experience around their working environment at the present- and with regard to the future employment status. Multivariable analyses revealed that especially psychological and cognitive deficits, but also pain and vision disturbances (the so-called “hidden symptoms” of MS) are particularly related to workplace problems of employed PwMS. With regard to working environment and potential work obstacles a case management strategy may improve working situation considerably and optimize not only the quality of life of PwMS, but also the economic situation for employers.

Author Contributions

Christiane Sterz – Conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Critical revision of the article, Final approval of the version to be published

David Ellenberger – Analysis and interpretation of data, Drafting the article, Critical revision of the article, Final approval of the version to be published

Heike Meissner – Analysis and interpretation of data, Critical revision of the article, Final approval of the version to be published

Tim Friede – Conception and design, Analysis and interpretation of data, Drafting the article, Critical revision of the article, Final approval of the version to be published

Peter Flachenecker – Conception and design, Analysis and interpretation of data, Drafting the article, Critical revision of the article, Final approval of the version to be published

Guarantor

The corresponding author is the guarantor of submission.

Conflict of Interest

Authors declare no conflict of interest.

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