

# Coping strategies in relation to negative work events and accommodations in employed multiple sclerosis patients

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## Abstract

**Background:** Job loss is common in multiple sclerosis (MS) and is known to exert a negative effect on quality of life. The process leading up to job loss typically includes negative work events, productivity losses and a need for accommodations. By using active coping strategies job loss may be prevented or delayed.

**Objective:** Our goal was to examine negative work events and accommodations in relation to coping strategies in employed relapsing–remitting MS patients.

**Methods:** Ninety-seven MS patients (77% females; 21–59 years old) completed questionnaires concerning the patient's work situation, coping strategies, demographics, physical, psychological and cognitive functioning. Forward binary logistic regression analyses were conducted to examine coping strategies and other (disease) characteristics predictive of reported negative work events and accommodations.

**Results:** Nineteen per cent of the employed MS patients reported one or more negative work events, associated with a higher use of emotion-oriented coping and more absenteeism. Seventy-three per cent reported using one or more work accommodations, associated with a higher educational level and more presenteeism. MS patients reporting physical changes to the workplace employed more emotion-oriented coping, while flexible scheduling was associated with task-oriented coping.

**Conclusion:** Emotion-oriented and task-oriented coping strategies are associated with negative work events and the use of accommodations.

**Keywords:** Multiple sclerosis, work, coping, negative work events, work accommodations, cognition

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## Introduction

Multiple sclerosis (MS) is an unpredictable, chronic disease affecting the central nervous system and is often diagnosed in young adulthood.<sup>1</sup> These are the prime years for developing and maintaining a working career. Several studies observed that more than half of the MS patients lose their jobs in the years following diagnosis.<sup>2,3</sup> The reasons for job loss are multi-faceted and depend on a mix of demographic, personal, disease-related and work factors.<sup>4–9</sup>

Recent studies have focused on the process of job loss in MS patients by monitoring the occurrence of negative work events and the use of accommodations.<sup>4,10–12</sup> As may be expected, both negative work events (e.g. formal discipline or verbal criticism for errors) and accommodations (e.g. physical aids) were found to be more common among employed MS patients than among healthy employees.<sup>12</sup> The presence of negative work events and accommodations was associated with measures of

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ambulation, cognition and depression in MS.<sup>4</sup> Among other variables, reporting a negative work event was found predictive of future job loss in MS patients.<sup>10</sup> This confirms the importance of monitoring the vocational situation of MS patients.

Coping strategies play an important role in health and well-being and refer to cognitive and behavioural efforts used to deal with stressful situations. The most common distinction is between task-oriented coping and emotion-oriented coping. The first is aimed at solving a problem, cognitively restructuring a problem or attempts to alter the situation. Emotion-oriented coping refers to self-oriented emotional reactions aimed to reduce stress, e.g. emotional responses, self-preoccupation and fantasising.<sup>13</sup> An additional distinction is between active and avoidant coping strategies, with the latter referring to activities and cognitive changes aimed at avoiding the stressful situation.

Previous studies have shown that emotion-oriented and avoidance strategies are generally maladaptive in chronic disease, while task-oriented coping is associated with better adjustment.<sup>14–17</sup> In a five-year follow-up study, recently diagnosed MS patients used fewer task-oriented and fewer emotion-oriented coping strategies in comparison with healthy controls. These coping styles further decreased in MS patients after five years.<sup>18</sup> One of the few MS studies examining employment in relation to coping strategies found that disability pensioned MS patients employed more social support for instrumental reasons, focused more on emotions, and showed more behavioural disengagement than MS patients still working at the five-year follow-up.<sup>18</sup> While some of these strategies may enhance patients' lives, too much focus on emotions and disengagement may lead to negative work outcomes. In another study among women with MS, maladaptive behavioural disengagement and substance use were, among other variables, related to being unemployed.<sup>19</sup>

In order to provide more insight in the process of job loss and related coping strategies, the current study examined the prevalence of negative work events and accommodations in employees with relapsing–remitting MS, and their associations with coping strategies. Possible associations with vocational, demographic and clinical characteristics were also examined. We hypothesised that negative work events are associated with dysfunctional coping styles (i.e. less task-oriented and more emotion-oriented and avoidance-oriented coping), while the use of accommodations is associated with functional

coping strategies (i.e. more task-oriented and less emotion-oriented and avoidance-oriented coping).

## Methods

### Participants

A total of 171 MS patients were recruited in the context of the MS@Work study via MS outpatient clinics in the Netherlands, a three-year follow-up study in Dutch patients with relapsing–remitting MS.<sup>20</sup> Inclusion criteria for the main study included (a) a diagnosis of relapsing–remitting MS according to the Polman-McDonald criteria of 2010,<sup>21</sup> (b) being 18 years and older and (c) being currently employed or within three years since their last employment. Patients with comorbid psychiatric or neurological disorders, substance abuse, neurological impairment that might interfere with cognitive testing or who were unable to speak and/or read Dutch were excluded from the study. We included 97 patients (77% females; 21–59 years old) who reported having a part-time or full-time paid job ( $N=135/171$ ), were not currently on sick leave ( $N=108/135$ ) and who completed the Coping Inventory for Stressful Situations (CISS) ( $N=97/108$ ). They completed online questionnaires and underwent neuropsychological and neurological examinations (data not currently available). The study was approved by the Medical Ethical Committee Brabant (NL43098.008.12 1307) and the board of directors of the participating MS outpatient clinics. All participants provided written informed consent.

### Vocational assessment

All participants completed a general questionnaire regarding demographics, disease characteristics, characteristics of current and previous jobs, absenteeism and presenteeism (i.e. self-reported influence of MS on work productivity). Questions pertaining to negative work events and accommodations were adapted from the Buffalo Vocational Monitoring Survey.<sup>4,10–12,22</sup> Six negative work events were specified and participants were asked to indicate whether they experienced such an event in the past three months. A list of 37 possible job accommodations was provided and participants were asked to indicate whether the accommodation was used at that time.

### Clinical assessment

Participants completed the physical functioning items from the Short Form-36 Health Survey.<sup>23</sup> The Multiple Sclerosis Neuropsychological Screening Questionnaire was used to measure self-reported

problems with cognitive and neuropsychiatric functioning.<sup>24</sup> Self-report measures of anxiety and depression were obtained using the Hospital Anxiety and Depression Scale.<sup>25</sup> The Modified Fatigue Impact Scale<sup>26</sup> was used to assess the impact of fatigue on daily functioning. The CISS<sup>13,27</sup> was used to examine preferred coping strategies in stressful or upsetting situations. This questionnaire examines three main coping strategies, i.e. task-oriented coping, emotion-oriented coping and avoidance-oriented coping.

### Statistical analysis

SPSS for Windows (release 23.0) was used for data analysis. MS patients were categorised as reporting or not reporting the presence or use of negative work events or accommodations. Due to skewed distributions, group differences in coping strategies, demographic, vocational and clinical characteristics were analysed using non-parametric Mann-Whitney *U* and Chi-squared tests. Binary logistic regression analysis (forward likelihood ratio method) was used to examine predictors of reported negative work events (i.e. reporting/not reporting negative work events) and reported accommodations (i.e. reporting/not reporting accommodations). As predictors we included variables that significantly differed between groups.

The accommodations were categorised into six types of accommodations.<sup>12</sup> On an exploratory basis we examined group differences in coping styles between MS patients reporting or not reporting the use of a certain type of accommodation, using Mann-Whitney *U*-tests and *t*-tests when appropriate. Due to the exploratory nature of this study, we used a lenient level of statistical significance of  $p \leq 0.05$  (two sided).

## Results

### Vocational assessment

The majority of the MS patients (83%) had a professional, administrative or management job. The others performed skilled manual labour. The participants worked for  $29.7 \pm 9.8$  hours per week, ranging from 12 to 55 hours. In comparison, in 2010 the Dutch employed labour force worked for 34.4 hours per week, with women working 28.4 hours per week (Dutch Central Bureau of Statistics; [www.cbs.nl](http://www.cbs.nl)). The majority of MS patients (81%) use immunomodulatory drugs. Regarding negative work events, 19% ( $N = 18$ ) reported one or more negative work events, with 14% ( $N = 14$ ) reporting one negative work event, 3% ( $N = 3$ ) reporting two events and 1% ( $N = 1$ ) reporting three events. Figure 1 displays the percentage of MS patients reporting a specific type of negative work event.

Regarding accommodations, 73% ( $N = 71$ ) reported using one or more accommodations. The number of accommodations ranged from 0 to 18, with a median number of 2.0 accommodations. The percentage of MS patients endorsing a specific type of accommodation is displayed in Figure 2.

### Negative work events vs. no negative work events

There were no group differences in most vocational characteristics, demographics, physical and psychological functioning (for more details see Table 1). Patients who experienced one or more negative work events reported more cognitive problems ( $U = 488.0$ ,  $p = 0.04$ ) and employed more emotion-oriented coping ( $U = 487.5$ ,  $p = 0.04$ ) than

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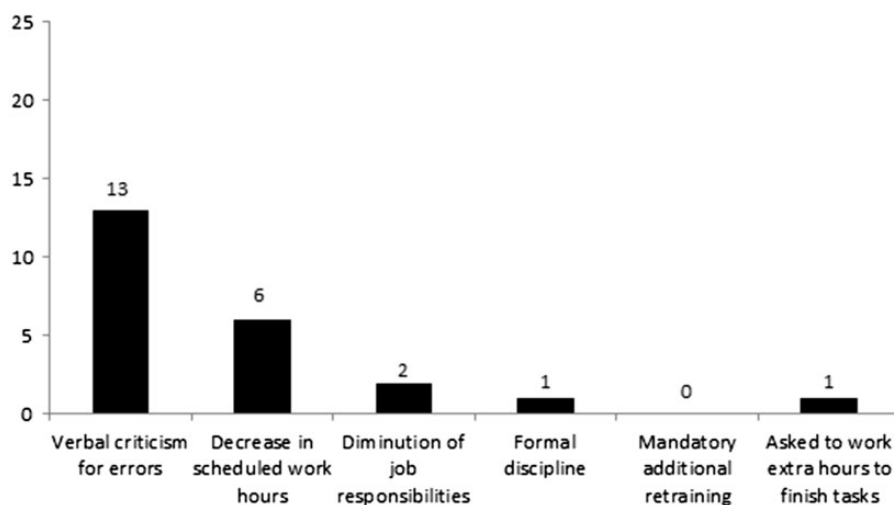
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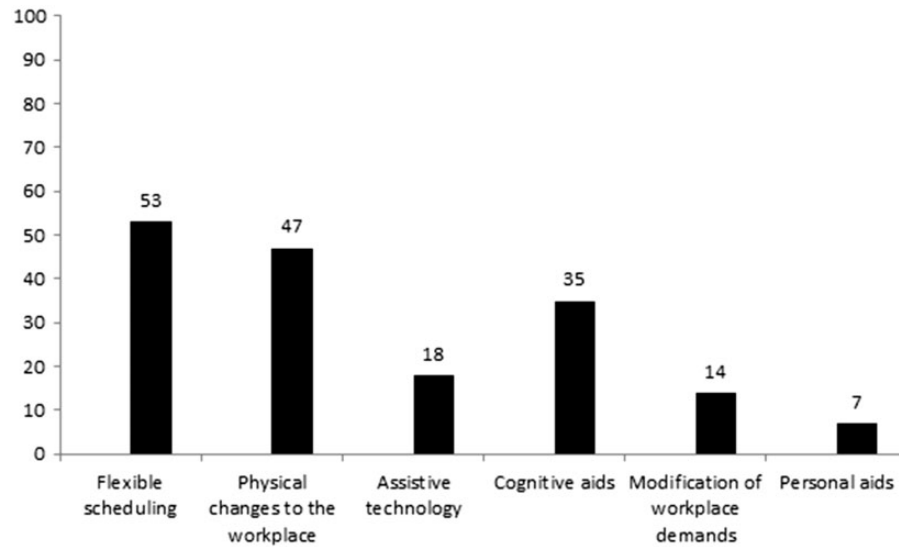
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**Figure 1.** Percentage of patients reporting a specific negative work event.



**Figure 2.** Percentage of patients using a specific type of work accommodation.

**Table 1.** Group differences between MS patients reporting and not reporting negative work events.

	Negative work events (N=18)	No negative work events (N=79)	p value
Gender (% females)	78%	77%	<i>p</i> = 0.96
Age	42.8 (10.6)	41.9 (9.1)	<i>p</i> = 0.54
Use of immunomodulators (%)	89%	80%	<i>p</i> = 0.37
Educational level <sup>a</sup> (median)	4.5	4.0	<i>p</i> = 0.80
Years in current position <sup>b</sup>	6.9 (6.3)	9.0 (8.3)	<i>p</i> = 0.39
Years with current employer <sup>c</sup>	14.3 (10.1)	11.8 (8.3)	<i>p</i> = 0.42
Number of paid hours	30.7 (8.4)	29.5 (10.2)	<i>p</i> = 0.59
Absenteeism <sup>d</sup>	2.4 (6.3)	0.1 (0.7)	<b><i>p</i> = 0.03</b>
Presenteeism <sup>e</sup>	3.4 (1.7)	2.4 (1.6)	<b><i>p</i> = 0.004</b>
Use of accommodations (%)	89%	70%	<i>p</i> = 0.10
Number of accommodations (median)	3.0	2.0	<i>p</i> = 0.09
Disease duration in years	9.0 (6.9)	8.1 (7.0)	<i>p</i> = 0.49
SF-36 PF scaled score	78.1 (22.6)	77.7 (21.7)	<i>p</i> = 0.99
MSNQ patient report	23.9 (10.9)	18.8 (8.7)	<b><i>p</i> = 0.04</b>
HADS depression	3.1 (2.5)	2.8 (2.4)	<i>p</i> = 0.67
HADS anxiety	6.2 (3.5)	4.8 (2.8)	<i>p</i> = 0.14
MFIS total	37.1 (17.2)	32.1 (14.8)	<i>p</i> = 0.24
CISS task-oriented coping	60.6 (9.1)	57.9 (8.9)	<i>p</i> = 0.12
CISS emotion-oriented coping	42.4 (12.8)	35.4 (9.8)	<b><i>p</i> = 0.04</b>
CISS avoidance-oriented coping	43.7 (10.3)	46.2 (9.4)	<i>p</i> = 0.24

Means (±standard deviation) are reported; Mann-Whitney *U* or Chi-squared tests were used to examine group differences; MS: multiple sclerosis; ns: not significant; <sup>a</sup>Educational level ranges from one (up to six years of primary education) to eight (postdoctoral); <sup>b</sup>Negative work events: *N* = 14, No negative work events: *N* = 57; <sup>c</sup>Negative work events: *N* = 14, No negative work events: *N* = 51; <sup>d</sup>Absenteeism: hours absent in the last seven days due to MS; <sup>e</sup>Presenteeism: degree of influence of MS on productivity in the last seven days (1–10); SF-36 PF: Short Form-36 Health Survey Physical Functioning; MSNQ: Multiple Sclerosis Neuropsychological Screening Questionnaire; HADS: Hospital Anxiety and Depression Scale; MFIS: Modified Fatigue Impact Scale; CISS: Coping Inventory for Stressful Situations.



patients who experienced no negative work events. Furthermore, absenteeism ( $U=615.0$ ,  $p=0.03$ ) and presenteeism ( $U=415.0$ ,  $p=0.004$ ) were higher in the group experiencing one or more negative work events.

#### *Accommodations vs. no accommodations*

There were no group differences in most vocational and demographic characteristics, coping strategies, physical, cognitive and psychological functioning. Educational level ( $U=687.5$ ,  $p=0.05$ ) and presenteeism ( $U=627.5$ ,  $p=0.01$ ) were higher in MS patients using accommodations vs. those not using accommodations. When looking more closely into coping strategies and specific types of accommodations, we found that MS patients reporting physical changes to their workplace employed more emotion-oriented coping ( $t(\text{degree of freedom})=-2.22$  (95),  $p=0.03$ ), while patients who used flexible scheduling used more task-oriented coping ( $U=709.5$ ,  $p=0.01$ ) than patients who did not report this type of accommodation.

#### *Predictors of negative work events and accommodations*

A binary logistic regression analysis (forward likelihood ratio method) was conducted to identify independent predictors of negative work events. Only variables that demonstrated a significant difference between groups were entered, i.e. self-reported cognitive functioning, emotion-oriented coping, absenteeism and presenteeism. The final model (Cox & Snell  $R^2=0.13$ ) included emotion-oriented coping ( $p=0.02$ ;  $B(\text{SE})=0.06$  (0.03); confidence interval (CI): 1.01–1.13) and absenteeism ( $p=0.07$ ;  $B(\text{SE})=0.32$  (0.17); CI: 0.97–1.93). The model correctly classified 86% of the cases.

A binary logistic regression analysis (forward likelihood ratio method) was conducted to identify independent predictors of accommodations. Only variables that demonstrated a significant difference between groups, were entered, i.e. educational level and presenteeism. The final model (Cox & Snell  $R^2=0.12$ ) included educational level ( $p=0.04$ ;  $B(\text{SE})=0.34$  (0.17); CI: 1.01–1.93) and presenteeism ( $p=0.02$ ;  $B(\text{SE})=0.54$  (0.22); CI: 1.10–2.66). The model correctly classified 76% of the cases.

## **Discussion**

Job loss is common in MS patients and may be prevented or delayed when identifying risk factors. The current study examined the occurrence of negative work events and accommodations in employed

Dutch MS patients and associated coping styles. We hypothesised that negative work events and accommodations would be associated with dysfunctional and functional coping styles respectively. Our hypotheses were partly confirmed in that more negative work events were associated with a higher use of emotion-oriented coping. MS patients reporting physical changes to the workplace employed more emotion-oriented coping, while flexible scheduling was associated with task-oriented coping.

#### *Negative work events*

We found that 19% of the MS patients reported one or more negative work events, with ‘verbal criticism for errors’ being the most frequently mentioned, followed by a ‘decrease in scheduled work hours’. In previous research, 30%–33% of employed MS patients reported negative work events.<sup>4,12</sup> This percentage may be higher because of the inclusion of progressive MS patients in these studies.

Frndak and colleagues (2015) found that specifically ‘verbal criticism for errors’ and ‘formal discipline’ distinguished MS patients who later lost their jobs from patients who maintained employment.<sup>10</sup>

MS patients who experienced negative work events also reported more absenteeism and presenteeism, worse cognitive functioning and more emotion-oriented coping as compared with MS patients reporting no negative work events. In a logistic regression model, increased use of emotion-oriented coping and more absenteeism were most predictive of negative work events. The aim of emotion-oriented coping is to reduce stress, and is oriented toward managing the emotions that accompany the perception of stress instead of dealing with the stressor itself. Reactions include emotional responses, self-preoccupation and fantasising.<sup>13</sup> Emotion-oriented coping is generally considered dysfunctional when coping with the consequences of a chronic disease, and is related to unemployment.<sup>14–16,18</sup> It should be noted that certain types of emotion-oriented coping, such as distancing, can have alleviating outcomes for a short period of time when stressors seem to be uncontrollable.<sup>28</sup> Whereas task-oriented coping mechanisms may allow individuals greater perceived control over their problem, emotion-oriented coping may lead to a reduction in perceived control. In this cross-sectional design, it is unclear whether the patient’s emotion-oriented coping style preceded the negative work event, or represented a reaction to a seemingly uncontrollable stressor. Unexpectedly, task-oriented and avoidance coping were unrelated to negative work events.

Perhaps changes in these types of coping occur later in the process of job loss.

MS patients reporting negative work events also reported higher levels of absenteeism and presenteeism, with absenteeism being most predictive of negative work events. It seems intuitive that absenteeism is related to negative work events. A ‘decrease in scheduled work hours’ might be a reaction to the employee calling in sick on a frequent basis. To further examine this relation, we need to monitor absenteeism over a longer period of time.

Interestingly, variables that were previously found to be related to negative work events, such as slower ambulation and greater depression, were unrelated in the current study.<sup>4</sup> In this respect it should be noted that we used different instruments and that a previous study included progressive MS subtypes. Consistent with the study by Benedict and colleagues (2014),<sup>4</sup> MS patients reporting negative work events also reported more cognitive problems. Self-reported cognitive performance was, however, not included as a main predictor of negative work events, as the final model favoured emotion-oriented coping and absenteeism. In a future study it would be best to include actual cognitive performance, particularly the Symbol Digit Modalities Test, which was the most discriminating cognitive task in distinguishing between Work-Stable and Work-Challenged MS patients.<sup>22</sup>

#### *Work accommodations*

Concerning accommodations we found that 73% of the patients in our sample reported using one or more accommodations, with 53% of the patients using flexible scheduling, in particular ‘being allowed to work from home’ and having ‘flexible work hours’. Physical changes to the workplace were reported by 47%, with ‘access to an air conditioner or fan’, ‘access to a refrigerator’ and ‘an ergonomic workplace/work station’ being most frequently reported. Cognitive aids were used by 35% with ‘prioritised job assignments’ being the most frequently reported. The median number of used accommodations (2.0) is relatively high, and comparable to the number of accommodations used by MS patients prior to job loss in the study by Frndak et al. (2015).<sup>10</sup> However, as the current study did not include a control group of healthy employees, we should be careful in drawing any conclusions.

We observed a higher educational level and more presenteeism in MS patients using one or more accommodations compared with those not reporting

accommodations. Both variables were significant predictors of accommodations in a logistic regression model. In 2008–2009 many employers in the Netherlands offered working remotely (‘het nieuwe werken’) creating the option for their employees to work in an efficient manner independent of time and place.<sup>29</sup> The most frequently mentioned type of accommodation (‘flexible scheduling’) is compatible with this type of working. Remote working is also more common in the type of jobs corresponding with a higher educational level, which may explain the observed relation between educational level and accommodations. Another possibility is that higher-educated individuals are more aware of the possibility to ask for appropriate accommodations at their workplace. It is worthwhile to educate MS patients about this option.

More presenteeism in the past week, i.e. a higher influence of MS-related symptoms on productivity while at work, was also related to the use of accommodations. This relation was found while none of the physical, cognitive or psychological variables was related to the use of accommodations.

The concept of presenteeism combines the perceived effect of all MS-related symptoms on work productivity. In relapsing–remitting MS patients, relations were found between presenteeism and increased disability, fatigue, depression, anxiety and reduced quality of life.<sup>30</sup> It makes sense that more accommodations are needed when disease-related symptoms have an increased perceived influence on work productivity. The observation that presenteeism was higher in MS patients using accommodations vs. those not using accommodations may suggest that the accommodations fail to fully compensate for the negative effects of MS on productivity. Presenteeism may provide an interesting additional measure for vocational monitoring purposes. It should be noted that based on our current experience, the Buffalo Vocational Monitoring Survey<sup>4,10–12,22</sup> applies well to the Dutch situation.

Although no relations were found between coping styles and the use of accommodations in general, we found more emotion-oriented coping in patients reporting physical changes to their workplace. Many of the frequently reported physical accommodations, i.e. ergonomic work stations, access to a refrigerator or fan, are often already available at the workplace. They mostly do not require a personal request from the employee. Physical accommodations were previously found to be more common in MS patients prior to job loss compared with MS patients who retained

their job<sup>10</sup> and may reflect increased disease severity. Their use may trigger negative illness perceptions, e.g. patients considering their illness as a serious condition and having a diminished sense of control, which is related to more emotion-oriented coping.<sup>28</sup> This is purely hypothetical and needs to be further explored in a larger sample monitored over time.

We observed more task-oriented coping in patients who used flexible scheduling. In order to realise and maintain flexible scheduling in a work situation, effective communication is needed between the employer, employee and colleagues. In the study by Frndak *et al.* (2015)<sup>10</sup> flexible scheduling was used to a similar degree by healthy controls and MS patients and seems to represent a 'healthy' work situation. A task-oriented coping style on the employee's side is beneficial in this situation, and possibly reflects a higher sense of self control. A study in chronic fatigue syndrome found that patients feeling a sense of control over their illness are less likely to engage in avoidant coping and more readily utilise task-oriented coping, relating to better health outcomes.<sup>17</sup>

### Limitations

The current study lacks a healthy control group and therefore we cannot be certain whether the reported negative work events and accommodations are related to having MS. Also, the study would benefit from including a battery of neuropsychological and neurological tests to examine cognitive and physical functioning in a more objective manner. Lastly, the current study has a cross-sectional design while it would be very informative to examine coping styles in relation to clinical changes and work problems over time. In the CISS, coping styles are viewed as a personality trait or preferred style of dealing with stressful situations. Nevertheless, coping styles may change over time in MS patients<sup>18</sup> and were found to be related to disease course,<sup>31</sup> exacerbations,<sup>32</sup> depression<sup>33</sup> and executive functioning.<sup>34</sup>

In summary, we found that the use of emotion-oriented coping was related both to negative work events and a higher usage of physical changes to the workplace, while more task-oriented coping was observed in patients using flexible scheduling. Although causal relations remain unclear, this study provides preliminary evidence for the beneficial effect of a more task- and less emotion-oriented coping style in the work situation. In the current sample, coping styles seem more influential in workplace challenges than self-reported cognition, physical abilities, fatigue and depression. Coping styles

can be learned and have been successfully trained in the past in relation to work.<sup>35</sup> Longitudinal studies on work and coping in the MS population are needed and may open the possibility to (internet-based) interventions focused on enhancing adequate coping styles and targeting negative illness perceptions. In addition, employees might benefit from adequate information about requesting appropriate work accommodations.

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RHB Benedict receives research support from Accorda, Novartis, Genzyme, Biogen, and Mallinckrodt Pharmaceuticals, is on the speakers' bureau for EMD Serono (designing CME courses), consults for Biogen, Genentech, Genzyme and Novartis, and receives royalties from Psychological Assessment Resources.

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