

## Factors related to employment status changes in individuals with multiple sclerosis

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*In a sample of 50 individuals with multiple sclerosis (MS), participants able to work full-time ('W'), those who reduced their hours ('CB') and those who were unemployed ('NW') were compared on demographic and disease variables and symptoms that the participants identified as being responsible for their work status change. The NW group had significantly greater physical disability than the other two groups and significantly more fatigue than the W group. The CB group had significantly more years of education and higher occupational prestige ratings than the NW group. The W group reported significantly greater mood disturbance compared with the NW group. Employment status was unrelated to age, gender, full scale IQ estimate, disease duration, diagnosis duration or cognitive functioning. Ninety per cent of the CB group reported that fatigue was a primary symptom responsible for their work status change, whereas 86% of the NW group reported that broad physical/neurological symptoms were responsible for their change in work status.*  
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### Introduction

Unemployment rates in individuals with multiple sclerosis (MS) have been shown to be as high as 80%.<sup>1</sup> Being unable to work full time can have a dramatic impact on an individual's self-concept and brings with it the threat of financial difficulties and increased stress on the part of caregivers, as well as the need to re-evaluate life goals defined through professional achievement. Not surprisingly, research has demonstrated that work status has been found to be related to quality of life ratings.<sup>2</sup> The unpredictable nature of the distribution and severity of MS symptoms across and within individuals can cause havoc for individuals with MS who are struggling to maintain employment. It is extremely difficult to predict disease outcome to any extent, much less with the accuracy desired to aid patients in making major life decisions, such as employment status changes. When the additional stressor of increased medical costs is considered, many individuals with MS face a difficult choice between struggling to maintain employment and facing early retirement on disability. If clinicians are able to identify patients who may be at high risk for becoming unemployed, early interventions may insure that efforts are made to help these individuals compensate for their changing abilities. The present study provides an exploration of how specific MS symptoms and demographic

characteristics are related to employment status change in these patients.

Several studies have examined factors associated with work status change in MS. Increased age,<sup>3–5</sup> greater physical disability<sup>3–6</sup> and less education<sup>3,4,6</sup> have been found to be related consistently to unemployment in MS. Factors that have less consistent support include gender (males more likely to be employed<sup>6</sup>), cognitive deficits<sup>5</sup> and greater diagnosis duration.<sup>5,7</sup> Depression has been found to be related consistently to unemployment in general population samples,<sup>8,9</sup> but not in MS.<sup>5</sup>

One limitation of previous work is that, to our knowledge, no MS study has examined factors associated with having to cut back one's employment versus those associated with complete unemployment. Identifying variables that distinguish patients who cut back on their work hours should provide valuable information concerning factors that may make it possible for people with MS to continue working, albeit at a reduced number of hours, versus having to quit working altogether. Such knowledge could be applied early on in the disease process to assist those with MS who wish to continue working as long as possible. The present study compares groups of people with MS who: 1) are still able to work full-time (W); 2) had to cut back on their hours due to their MS symptoms (CB); and 3) had to leave their jobs entirely due to their MS symptoms (NW). More specifically, the present study examines whether these three groups lie on a spectrum of disease severity, with the unemployed group experiencing the most severe physical, cognitive or affective symptoms, or if these three groups represent different patterns of symptomatology. For example, do certain symptoms make it more difficult to work than others and can certain symptoms be managed by working

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fewer hours? The symptoms participants in the CB and NW groups reported to be most responsible for their employment status change were examined and the groups were also compared on objective measures of these symptoms. Lastly, this study examined possible cognitive differences between these three groups using neuropsychological measures. Because of the absence of prior research on patients cutting back on their work hours, our study was purely descriptive in nature, and thus we made no *a priori* hypotheses.

## Methods

### Participants

The initial phase of the study examined neuropsychological functioning in individuals with MS. The participants were recruited from neurologists and local MS support groups in the northwestern USA. Exclusion criteria included a history of substance abuse, nervous system disorder other than MS, severe motor or visual impairment that would interfere with cognitive testing, pre-morbid history of a learning disability, severe physical or neurological impairment that made testing at the university location impossible or inability to come to the testing centres due to distance. [For a more detailed account of the participants included, see Arnett *et al.*<sup>10</sup>]

All participants provided informed consent and were treated in accordance with the ethical standards of the American Psychological Association. They were also provided with a written neuropsychological evaluation of their performance as well as verbal feedback at the completion of their participation. Each participant was diagnosed with definite or probable MS by a board-certified neurologist using Poser *et al.*'s criteria.<sup>11</sup> Disease course was classified according to Lublin and Reingold's suggested criteria.<sup>12</sup> Participants' disability levels were also rated using a self-report adaptation of Kurtzke's Expanded Disability Status Scale (EDSS),<sup>13</sup> which was developed in consultation with a board-certified neurologist. No participants were experiencing an exacerbation at the time of testing.

Out of the 77 original participants, by the point of second contact, 1 was deceased, 12 were not interested in participating in the second phase and 10 could not be contacted. One participant discontinued participation in the second portion of the study after having a negative reaction to the cognitive testing. Three other participants were eliminated because they were unemployed for reasons other than their MS symptoms. The remaining group of 50 patients consisted of 12 men (24%) and 38 women (76%), all Caucasians. The mean age was 49.88 years (SD = 7.59), the mean number of years since diagnosis was 10.26 (SD = 6.03) and the mean number of years since the first symptom was 16.76 (SD = 9.41). Participants included 47 people with clinically definite MS, 1 person with lab definite MS and 2 people with clinically probable MS. The majority of the patients were right-handed (46, 92%) and married (44, 88%). Their average level of education was 15.48 years (SD = 2.49). There were

19 participants (38%) in the W group, 10 in the CB group (20%) and 21 in the NW group (42%).

### Procedure

Only participants from the second time point in the longitudinal study were included in the present study. Participants were mailed a packet of questionnaires to complete in the week prior to their testing day. On the day of testing, the participants were interviewed by clinical psychology graduate students who completed a brief psychosocial interview prior to any test administration. Following this interview, participants completed the depression, fatigue and cognitive measures.

### Cognitive measures

*Measures included in cognitive summary index* The Controlled Oral Word Association test (COWA) measures verbal association fluency.<sup>14</sup> The 7/24 Spatial Recall is a test of visuospatial memory.<sup>15</sup> The verbal selective reminding test (SRT) measures word-list learning.<sup>16</sup> The PASAT measures sustained attention, mental tracking, working memory and speeded information processing.<sup>17</sup> The Tower of Hanoi test is a visual puzzle task sensitive to planning deficits.<sup>15</sup> In the present study, a computerized version was used.<sup>18</sup> Participant scores are based on their total number of moves and their total time from four trials presented in two blocks, approximately 30 minutes apart.<sup>19</sup> These scores are highly correlated and were combined in analysis to form a total time score and a total move score. The Symbol-Digit Modalities Test (SDMT) (oral form) is a task measuring complex scanning and visual tracking as well as working memory.<sup>20</sup>

The selection of these particular cognitive tasks follows from a recent consensus agreement recommending a core battery, the Minimal Assessment of Cognitive Function in MS (MACFIMS), for assessing cognitive functioning in MS. This battery includes tasks that measure processing speed/working memory, learning and memory, executive functions, visual perception/spatial processing, and language.<sup>21</sup> Additionally, most of the tests selected in the current study are the components of the Brief Repeatable Battery of Neuropsychology Tests in Multiple Sclerosis (BRB-N),<sup>22</sup> though the 7/24 spatial recall test is used in this study rather than the 10/36 spatial recall test suggested for the BRB-N.

*IQ measure* The Shipley Institute of Living Scale is a paper-and-pencil test of vocabulary and verbal abstraction<sup>23</sup> that is highly correlated with Wechsler Adult Intelligence Scale-Revised (WAIS-R)<sup>24</sup> full scale IQ scores.<sup>25</sup>

### Psychosocial measures

Because previous research in other literature (e.g., Reisine *et al.* and Yelin *et al.* in the rheumatoid arthritis literature<sup>26,27</sup>) has suggested a link between SES and work status changes, participant job titles were coded using the Hollingshead scale and the groups were compared.<sup>28</sup> The Hollingshead Four-Factor Index of Social

Status is a system for characterizing the socioeconomic status of an individual based on gender, marital status, years of education and occupation.<sup>28</sup> For the purposes of this study, only the numerical scores given to the participants' occupations based on Hollingshead's recommendations were used because the variables of marital status, age and gender were considered separately. Hollingshead's system provides a nine-step scale for rating occupational titles based on the 1970 United States Census. For example, the scale ranges from a score of 9 for psychologists, to a 5 for bank tellers, to a 1 for dishwashers.<sup>28</sup> Both participants' most recent (or current) jobs and the jobs on which they held the most responsibility (by self-report) were coded for analysis.

The psychosocial interview includes several questions regarding participant demographics, education and employment history. Participants were asked directly if they had quit their jobs or cut back on their hours due to their MS symptoms. Participants who indicated that they quit their jobs or cut back on their hours were asked to specify what symptom or symptoms were most responsible for this change in their employment status.

#### *Disability, fatigue and depression measures*

The Fatigue Impact Scale (FIS) examines the impact of MS-related fatigue on daily activities.<sup>29</sup> Patients rate the extent to which fatigue has interfered with their day to day functioning in regard to 40 exemplar statements. Though previous research has revealed that, when asked, a large number of individuals with MS report fatigue to be a causal factor in their work status changes,<sup>4,6</sup> this relationship has not been examined using objective self-report measures.

The Beck Depression Inventory (BDI) is a 21-item, self-rated measure of depression.<sup>30</sup> The Chicago Multiscale Depression Inventory (CMDI) is a 42-item self-rated depression inventory developed for use in medical patient populations.<sup>31,32</sup> It is composed of mood, evaluative and vegetative subscales. Consistent with our prior work<sup>33-35</sup> and the recommendation of other investigators,<sup>32</sup> only the nonvegetative scales from the CMDI were used to avoid the potential overlap between vegetative depression symptoms and MS symptoms.

## Results

The data were initially examined to determine missing cases. For the data manipulations reported below, the following measures had two participants with missing data: EDSS, PASAT-3 and the Tower of Hanoi. No participants were missing more than one data point and all other cases had complete information.

Chi square tests for independence for sex, marital status (married versus unmarried) and course type could not be performed considering the participants as three work status groups due to small cell sizes. For this reason, chi square tests were performed for these variables using the work status groups collapsed into employed (W and CB) versus unemployed (NW) and separately for employed

full-time (W) versus reduced employment (CB and NW). As the CB group has not previously received research attention, a liberal approach was used in determining whether it should be categorized with participants who were working or those who were not. Chi-square tests for independence revealed no significant differences for sex ( $\chi^2(1, n=50)=0.01, P>0.05$ ) or marital status ( $\chi^2(1, n=50)=0.18, P>0.05$ ) between the employed and unemployed groups. Additionally, there were no significant differences for sex ( $\chi^2(1, n=50)=0.09, P>0.05$ ) or marital status ( $\chi^2(1, n=50)=0.06, P>0.05$ ) between the employed full-time and reduced employment groups. Because of the small  $n$  in the primary progressive and progressive relapsing groups, analyses were conducted using only relapsing-remitting and secondary progressive patients. This analysis was significant when comparing the employed versus unemployed groups ( $\chi^2(1, n=43)=7.09, P<0.01$ , Fisher's Exact Test), with a higher than expected number of participants with secondary progressive MS in the NW group. However, this analysis was not statistically significant when the employed full-time and reduced employment groups were compared ( $\chi^2(1, n=43)=3.68, P>0.05$ , Fisher's Exact Test) (Table 1).

Four multivariate analysis of variance (MANOVA) tests were performed to compare the three groups on continuous demographic and disease variables. Variables were grouped together based on a rational analysis of their relatedness.

The first MANOVA compared the employment status groups on years of education, WAIS-R full scale IQ, Hollingshead scale ratings for the participants' current or (in the case of the NW group) most recently held occupation and Hollingshead scale ratings for the occupation on which the participants reported the most responsibility. The multivariate test was statistically significant [Lambda (8, 90)=2.35,  $P<0.05$ ]. Significant ( $P<0.05$ ) univariate results were found for years of education and Hollingshead scale ratings for the occupations on which the participants held the most responsibility. Tukey's Honestly Significant Difference (HSD) post hoc test revealed that the CB group had significantly more education than the NW group. Compared with the NW group, the CB group had significantly higher ratings on the Hollingshead scale for the occupations on which the participants held the most responsibility. The W group was not significantly different from either of the two other groups on either variable (See Table 2).

The next MANOVA compared the employment status groups on age, years of symptom duration and years since diagnosis. Because the MANOVA was not statistically significant [Lambda (6, 90)=1.65,  $P>0.05$ ], the univariate tests were not examined.

The third MANOVA compared the groups on EDSS and FIS scores. The multivariate test was statistically significant [Lambda (4, 88)=7.48,  $P<0.001$ ], and univariate tests were significant for the EDSS and FIS scores. Tukey's HSD post hoc test revealed significantly higher EDSS scores for the NW group compared with both the W and CB groups, and significantly higher FIS scores for the NW versus the W group.

Table 1 Demographics

	Working (n = 19)	Cut back (n = 10)	Not working (n = 21)
Sex	14 (73.7%) Female	8 (80%) Female	16 (76.2%) Female
Course type	14 (73.7%) R-R 3 (15.8%) SP 2 (10.5%) PP 0 (0%) PR	7 (70%) R-R 2 (20%) SP 1 (10%) PP 0 (0%) PR	7 (33.3%) R-R 10 (47.6%) SP 3 (14.3%) PP 1 (4.8%) PR
Marital status	17 (89.5%) married/cohabitating 2 (10.5%) divorced 0 (0%) widowed 0 (0%) single	9 (90%) married/cohabitating 0 (0%) divorced 0 (0%) widowed 1 (10%) single	18 (85.7%) married/cohabitating 1 (4.8%) divorced 2 (9.5%) widowed 0 (0%) single

The multivariate test comparing the employment status groups on BDI, CMDI Mood scale and CMDI Evaluative scale scores was significant [ $\Lambda(6, 90) = 2.30, P < 0.05$ ]. The follow-up univariate ANOVAs revealed non-significant results for the BDI and for the CMDI Evaluative scale. However, the univariate results for the CMDI Mood scale revealed a significant difference between the three groups. Tukey HSD tests revealed significantly higher CMDI Mood scale scores for the W group compared with the NW group, and a tendency ( $P < 0.10$ ) towards the W group having higher scores on the CMDI Mood scale than the CB group as well.

A multivariate analysis of covariance (MANCOVA) was performed with scores on the PASAT, SDMT, SRT, Tower of Hanoi, COWA and the 7/24 Spatial Recall Task as dependent variables. Age, depression (as measured by the CMDI Mood and Evaluative Scales and the BDI), use of drugs that may affect cognition and years of education were used as the covariates. The multivariate test of the MANCOVA was nonsignificant [ $\Lambda(16, 58) = 0.68, P > 0.05$ ].

Preliminary examination of participants' interview responses about symptoms responsible for their work status change revealed that the symptoms could be grouped into the following categories: fatigue, broad physical/neurological symptoms and cognitive symptoms. Because many participants endorsed more than one symptom as being responsible for their change in work status, responses were coded as yes/no for each symptom category. For example, if a participant responded that she had to quit her job due to short-term memory difficulties and hand numbness, her response would be coded as yes to cognitive symptoms, yes to broad physical/neurological symptoms and no to fatigue. Chi-square analysis revealed that significantly more participants in the NW group reported broad physical/neurological symptoms as the symptoms most responsible for work status change ( $\chi^2(1, n = 31) = 9.62, P < 0.01$ , Fisher's Exact Test). Additionally, compared with the NW group, significantly more participants in the CB group reported fatigue as the most responsible for work status change ( $\chi^2(1, n = 31) = 8.71, P < 0.01$ , Fisher's Exact Test). There was no significant difference between the NW and CB groups on

Table 2 MANOVA results

	Working M (SD)	Cut back M (SD)	Not working M (SD)	F	P
MANOVA 1					
Years of education	15.26 (0.50)	17.20 <sub>a</sub> (0.69)	14.48 <sub>b</sub> (0.48)	(2, 47) = 5.27	< .01
FSIQ <sup>a</sup>	105.00 (1.79)	109.50 (2.48)	104.71 (1.71)	(2, 47) = 1.41	ns
Hollingshead Current	5.74 (0.46)	6.80 (0.63)	5.57 (0.44)	(2, 47) = 1.37	ns
Hollingshead Responsibility	5.84 (0.43)	7.40 <sub>a</sub> (0.59)	5.62 <sub>b</sub> (0.41)	(2, 47) = 3.33	< .05
MANOVA 2: multivariate test not significant					
Age	48.32 (1.69)	47.20 (2.33)	52.57 (1.61)		
Diagnosis duration	8.42 (1.35)	9.50 (1.86)	12.29 (1.28)		
Symptom duration	13.26 (2.07)	15.60 (2.85)	20.48 (1.97)		
MANOVA 3					
EDSS <sup>b</sup>	3.47 <sub>a</sub> (0.30)	4.25 <sub>a</sub> (0.40)	5.73 <sub>b</sub> (0.28)	(2, 45) = 15.52	< .001
FIS <sup>c</sup>	32.89 <sub>a</sub> (6.89)	43.70 (9.23)	66.60 <sub>b</sub> (6.53)	(2, 45) = 6.54	< .01
MANOVA 4					
CMDI <sup>d</sup> Mood	27.26 <sub>a</sub> (2.07)	19.40 (2.85)	20.38 <sub>b</sub> (1.97)	(4, 27) = 3.80	< .05
CMDI Evaluative	18.79 (1.25)	17.90 (1.72)	16.67 (1.19)	(4, 27) = 0.77	ns
BDI <sup>e</sup>	8.32 (1.27)	7.30 (1.75)	9.10 (1.21)	(4, 27) = 0.36	ns

Means with different subscripts are significantly different at  $P < 0.05$  in the Tukey HSD comparison.

'Hollingshead Responsibility' refers to the Hollingshead rating made based upon the participants' highest job status obtained at any point in life.

<sup>a</sup>Full Scale IQ, <sup>b</sup>Kurtzke's Extended Disability Status Scale, <sup>c</sup>Fatigue Impact Scale, <sup>d</sup>Chicago Multiscale Depression Inventory, <sup>e</sup>Beck Depression Inventory.

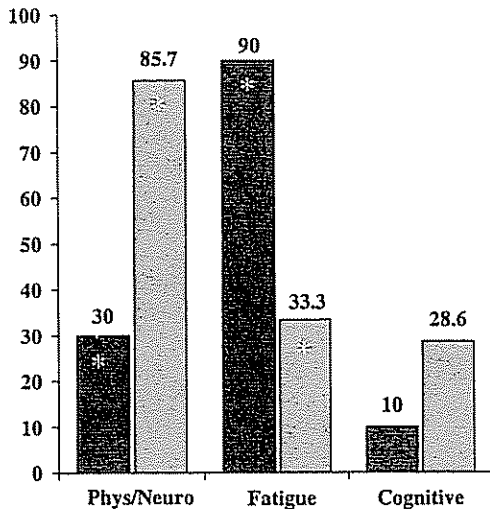


Figure 1 Percentage of cut back and not working participants reporting symptoms most responsible for work status change (\* $P < 0.01$ ).

participants reporting cognitive symptoms as requiring work status change, ( $\chi^2 (1, n = 31) = 1.34, P > 0.05$ , Fisher's Exact Test) (See Figure 1).

## Discussion

### Summary

The present study was designed to examine the differences between three groups of people with MS: one that maintained full-time employment, one that cut back on hours due to MS symptoms and one that was unemployed due to their MS symptoms. This sample, much like that of Beatty *et al.*'s,<sup>5</sup> reflects a higher percentage (38%) of participants who were employed full time than in previous research, most likely due to the fact that this sample was less disabled and more educated than those included in earlier studies.<sup>4,6,7</sup> Though previous research has examined unemployed versus employed groups in MS, people that cut back (CB group) on their employment hours have not been considered separately.

It was suggested that these groups might lie on a spectrum of disease severity, with the unemployed group experiencing the most severe symptoms, that these three groups might differ on important socioeconomic factors, and that specific patterns of symptomatology might be related to work status in different ways. Although most of the present results supported previous research on employed versus unemployed patients, there were significant differences between the CB group and the W and NW groups, suggesting that these differences may have confounded the results of previous research into employment in MS that collapsed the CB group into categories of employed versus unemployed.

Again, the factors that have been consistently related to work status change in MS include age, physical disability and education; gender, cognitive deficits and diagnosis duration have had less consistent support.<sup>3-6</sup>

In the present study, we found that the NW group had significantly higher ratings of physical disability than the CB and W groups, supporting previous research findings. We also found that the NW group had significantly higher scores on an objective measure of fatigue than the W group. While prior studies have shown that individuals with MS who are unemployed report fatigue to be a major factor,<sup>4,36</sup> this has not (to our knowledge) been demonstrated previously with an objective measure of fatigue.

Compared with the NW group, the CB group had significantly more years of education and higher Hollingshead scale ratings for the occupation on which the participants held the most responsibility. Because of their higher degree of education and higher level of prestige in their work experience, individuals in the CB group may have had more latitude to cut back on their hours or to reconfigure their positions to adapt to their MS. Given their higher level of education and higher level of occupational prestige, it may be that the CB group was more financially secure than the NW group and may have been able to make the decision to work at reduced hours rather than having to retire on disability.

The data revealed no significant differences between genders, unlike LaRocca *et al.*,<sup>6</sup> who found that males were more likely to remain employed. One possible explanation for this discrepancy between studies is that the data in the present study reflect the continual evolution of women's positions in the workplace. It may be that the female participants in the present study were raised with the expectation that they would be employed and were better able to find positions in fields of interest. Additionally, LaRocca *et al.* did not eliminate participants who were unemployed for reasons other than their MS symptoms (e.g., pregnancy, marriage) from the analysis, which may have contributed to the finding that men were more likely to remain employed in that sample.<sup>6</sup>

Though most previous research has failed to find significant differences between unemployed and employed samples on illness duration, there has been support for age as a predictor of unemployment. This was not supported in the present study. However, this may again be due to the fact that previous research did not remove people who were unemployed for reasons other than their MS symptoms from analysis, suggesting the possibility that individuals who retired from their occupations due to age alone may be driving this effect.

The current study revealed that when individuals with primary progressive and progressive relapsing MS were removed from the analysis, more individuals with secondary progressive MS were found in the NW group compared to the employed groups. This is not surprising, because secondary progressive MS is typically associated with greater physical disability than relapsing-remitting MS.

An unexpected finding in this study was the higher level of depressed mood in the W group compared with the NW group. Although the differences between these groups in depression did not emerge on the BDI, this may

be due to the fact that their MS symptoms (e.g., fatigue) overlap with vegetative symptoms of depression and differentially affected their BDI scores. When only mood symptoms were considered, individuals who were working reported a higher level of depression than those in the NW and CB groups (though only marginally significant for the CB group). This may be due to the fact that the demands of maintaining employment represent a significant stressor for individuals with MS and this puts them at greater risk for developing depressed mood. Future research comparing daily stressors in employed versus unemployed groups could evaluate this hypothesis directly.

When CB and NW participants were asked to indicate the symptoms most responsible for their work status change, an overwhelming majority (90%) of participants in the CB group reported that fatigue was responsible, compared with only 33% of the NW group. This pattern was neatly reversed for the broad physical/neurological category, with 86% of the NW group reporting broad physical/neurological symptoms as being responsible for their work status change as compared to 30% of the CB group. This striking separation in symptoms held responsible for changes in work status suggests that individuals with MS may be able to cope with fatigue by cutting back on their hours. In contrast, significant physical/neurological symptoms may interfere with job performance to such an extent that continuing in any capacity is precluded. These results correspond well with the findings that participants in the NW group displayed significantly more physical disability than their CB and W counterparts while the CB group's disability ratings were not significantly different from those in the W group. In terms of fatigue, the CB group may not have reported significantly more fatigue than the W group on the self-report measure of current fatigue because they were coping effectively with their fatigue by working less. It may be that the fatigue that was experienced by participants in the NW group was so severe that not even leaving employment could reduce it.

It was somewhat surprising that such a small percentage of participants (10% for the CB group and 29% for the NW group) reported that cognitive symptoms were responsible for their work status changes. Nonetheless, the results of the MANCOVA support this, as no significant differences were found between the groups on their scores on a variety of cognitive measures commonly found to detect impairment in MS. This is also consistent with the results of Edgley *et al.*,<sup>4</sup> who found that only 12% of their unemployed sample reported cognitive symptoms as a primary reason for having discontinued their employment. While Kalechstein *et al.* recently reported that cognitive functioning was associated with employment status,<sup>37</sup> patients with MS were not included in the review.

#### *Limitations and suggestions for future research*

Although the present study provides an examination of a previously overlooked work status group (those who have cut back on their work hours), there are limitations to the

conclusions that may be drawn. First, the sample size of the cut back group was relatively small ( $n=10$ ), making replication of our results essential before any firm conclusions can be drawn. Additionally, we did not include a measure of the physical, emotional and mental demands of the participants' occupations or their level of interest in their occupations. Furthermore, the possibility of secondary gain could be a factor in work status change for people with MS. Another factor that may contribute to MS patients' decisions to remain employed may be their or their spouses' level of insurance coverage. An individual may be forced to remain employed to maintain coverage or may be able to retire earlier if that coverage is more generous. This might also interact with premorbid financial status. Future research should include an investigation of these factors in order to examine the possible interaction between the demands of the participants' occupations and their interest in them with their ability to maintain their employment status.

As Kornblith *et al.* note, another likely factor in determining continued employment in MS populations that cuts across the occupational spectrum is the 'fit' of the individual's specific symptoms to the requirements of the occupation.<sup>3</sup> Certain symptoms, such as loss of visual acuity, may be devastating to an individual whose job depends on this skill, such as a jeweller.

Additionally, the cross-sectional design of the present study did not make it possible to examine whether participants in the NW group were once in the CB group. However, the significant differences between the CB group and the NW group on relatively fixed demographic factors such as years of education and Hollingshead scale ratings of occupational prestige suggest real differences between these groups. It is also possible that recall bias or response shift may have affected the responses of the participants. Response shift is defined as a change in an individual's self-assessment of a construct due to a change in conceptualization of a construct, a change in the importance or value of a construct, or a change in an individual's personal standards for measuring a construct,<sup>38</sup> while recall bias may be understood as recall distortion. Schwartz *et al.* (2004) have demonstrated that response shift and recall bias may affect reports of both fatigue and problems with ambulation.<sup>39</sup>

A final limitation concerns the possibility of selection bias given that we used a sample of convenience. Participants were recruited from MS support groups and neurologists. Those choosing to participate in the study and those being actively followed by neurologists may have had different characteristics than those who chose not to participate and were not currently seeing a neurologist. Nonetheless, the demographic and illness characteristics of our sample were comparable to many other studies that have been published in the MS literature.

In summary, this study offers a closer look at the complex factors influencing work status change in MS. It appears that, despite the changes in workplace accessibility, physical disability and fatigue are still major determinants of work status change in individuals with

MS. These findings also suggest that socioeconomic and demographic factors such as occupational prestige and years of education play an important role in the ability of individuals with MS to maintain their employment while coping with their MS symptoms by reducing their hours.

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### References

- 1 Scheinberg L, Holland N, LaRocca N, Laitin P, Bennett A, Hall H. Multiple sclerosis: earning a living. *NY State J Med* 1980; 80: 1395-400.
- 2 Koch LC, Rumrill PD, Roessler RT, Fitzgerald S. Illness and demographic correlates of quality of life among people with multiple sclerosis. *Rehabil Psychol* 2001; 46: 154-64.
- 3 Kornblith AB, LaRocca NG, Baum HM. Employment in individuals with multiple sclerosis. *Int J Rehabil Res* 1986; 9: 155-65.
- 4 Edgley K, Sullivan MJL, Dehoux E. A survey of multiple sclerosis. Part 2. Determinants of employment status. *Can J Rehabil* 1991; 4: 127-32.
- 5 Beatty WW, Blanco CR, Wilbanks SL, Paul RH, Hames KA. Demographic, clinical, and cognitive characteristics of multiple sclerosis patients who continue to work. *J Neurol Rehabil* 1995; 9: 167-73.
- 6 LaRocca N, Kalb R, Scheinberg L, Kendall P. Factors associated with unemployment of patients with multiple sclerosis. *J Chronic Dis* 1985; 38: 203-10.
- 7 Bauer HJ, Firnhaber W. Prognostic criteria in multiple sclerosis. *Ann NY Acad Sci* 1965; 122: 542-51.
- 8 Dooley D, Catalano R, Wilson G. Depression and unemployment: panel findings from the Epidemiological Catchment Area study. *Am J Community Psychol* 1994; 22: 745-65.
- 9 Üstün TB. The worldwide burden of depression in the 21st century. In Weissman M ed. *Treatment of depression: bridging the 21st century*. Washington, DC: American Psychiatric Press, 2001: 35-46.
- 10 Arnett PA, Higginson CI, Voss WD, Bender WI, Wurst JM, Tippin J. Depression in multiple sclerosis: relationship to working memory capacity. *Neuropsychology* 1999; 13: 546-56.
- 11 Poser CM, Paty DW, Scheinberg L, McDonald IW, Davis FA, Ebers GC et al. New diagnostic criteria for multiple sclerosis: guidelines for research protocols. *Ann Neurol* 1983; 13: 227-31.
- 12 Lublin FD, Reingold SC. Defining the clinical course of multiple sclerosis: results of an international survey. *Neurology* 1996; 46: 907-11.
- 13 Kurtzke JF. Rating neurologic impairment in multiple sclerosis: an expanded disability status scale (EDSS). *Neurology* 1983; 33: 1444-52.
- 14 Spreen O, Benton AL. *Neurosensory Center Comprehensive Examination for Aphasia: manual of directions*. Victoria, BC: Neuropsychology Laboratory, University of Victoria, 1969.
- 15 Lezak M. *Neuropsychological assessment*, third edition. New York: Oxford University Press, 1995.
- 16 Buschke H, Fuld PA. Evaluating storage, retention, and retrieval in disordered memory and learning. *Neurology* 1974; 24: 1019-25.
- 17 Gronwall DMA. Paced Auditory Serial-Addition Task: a measure of recovery from concussion. *Percept Mot Skills* 1977; 44: 367-73.
- 18 Goel V, Grafman J. Are the frontal lobes implicated in 'planning' functions? Interpreting data from the Tower of Hanoi. *Neuropsychologia* 1995; 33: 623-42.
- 19 Randolph JJ, Arnett PA, Freske P. Metamemory in multiple sclerosis: exploring affective and executive contributors. *Arch Clin Neuropsychol* 2003; 619: 1-21.
- 20 Smith A. *Symbol Digit Modalities Test (SDMT) Manual (Revised)*. Los Angeles, CA: Western Psychological Services, 1982.
- 21 Benedict RHB, Fischer JS, Archibald CJ, Arnett PA, Beatty WW, Bobholz J et al. Minimal neuropsychological assessment of MS patients: a consensus approach. *Clin Neuropsychol* 2002; 16: 381-97.
- 22 Rao SM, CFS Group, NMS Society. *A manual for the brief, repeatable battery of neuropsychological tests in multiple sclerosis*. New York, NY: National Multiple Sclerosis Society, 1990.
- 23 Zachary RA. *Shipley Institute of Living Scale: Revised Manual*. Los Angeles, CA: Western Psychological Services, 1986.
- 24 Wechsler D. *Manual for the Wechsler Adult Intelligence Scale - Revised*. New York, NY: Psychological Corporation, 1981.
- 25 Zachary RA, Crumpton E, Spiegel DE. Estimating WAIS-R IQ from the Shipley Institute of Living Scale. *J Clin Psychol* 1985; 41: 532-40.
- 26 Reisine S, Fifield J, Walsh S, Feinn R. Factors associated with continued employment among patients with rheumatoid arthritis: a survival model. *J Rheumatol* 2001; 28: 2400-408.
- 27 Yelin E, Meenan R, Nevitt M, Epstein W. Work disability in rheumatoid arthritis: effects of disease, social, and work factors. *Ann Intern Med* 1980; 93: 551-56.
- 28 Hollingshead AB. Four Factor Index of Social Status. Unpublished working paper. New Haven, CT: Yale University Department of Sociology, 1975.
- 29 Fisk JD, Ritvo PG, Ross L, Haase DA, Marrie TJ, Schlech WF. Measuring the functional impact of fatigue: initial validation of the Fatigue Impact Scale. *Clin Infect Dis* 1994; 18: S79-83.
- 30 Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. *Arch Gen Psychiatry* 1961; 4: 561-71.
- 31 Nyenhuis DL, Rao SM, Zajecka JM, Luchetta T, Bernardin L, Garron DC. Mood disturbance versus other symptoms of depression in multiple sclerosis. *J Int Neuropsychol Soc* 1995; 1: 291-96.
- 32 Nyenhuis DL, Luchetta T, Yamamoto C, Terrien A, Bernardin L, Rao SM et al. The development, standardization, and initial validation of the Chicago Multiscale Depression Inventory. *J Pers Assess* 1998; 70: 386-401.

- 33 Arnett PA, Rao SM, Grafman J, Bernardin L, Luchetta T, Binder J *et al.* Executive functions in multiple sclerosis: an analysis of temporal ordering, semantic encoding, and planning abilities. *Neuropsychology* 1997; 11: 535–44.
- 34 Arnett PA, Higginson CI, Randolph JJ. Depression in multiple sclerosis: relationship to planning ability. *J Int Neuropsychol Soc* 2001; 7: 665–74.
- 35 Arnett PA, Higginson CI, Voss WD, Randolph JJ. Relationship between coping, depression, and cognitive dysfunction in multiple sclerosis. *Clin Neuropsychol* 2002; 16: 341–55.
- 36 Jackson M, Quaal C, Reeves M. Effects of multiple sclerosis on occupational and career patterns. *Axon* 1991; 13: 16–22.
- 37 Kalechstein AD, Newton TF, van Gorp WG. Neurocognitive functioning is associated with employment status: a quantitative review. *J Clin Exp Neuropsychol* 2003; 25: 1186–91.
- 38 Sprangers M, Van Dam F, Broersen J, Lodder L, Wever L, Visser MRM *et al.* Revealing response shift in longitudinal research on fatigue. *Acta Oncol* 1999; 38: 709–18.
- 39 Schwartz CE, Sprangers M, Carey A, Reed G. Exploring response shift in longitudinal data. *Psychol Health* 2004; 19: 51–69.