



## Negative work events reported online precede job loss in multiple sclerosis



Seth E. Frndak, Lauren N. Irwin, Victoria M. Kordovski, Kristen Milleville, Carrie Fisher, Allison S. Drake, Ralph H.B. Benedict<sup>\*</sup>

Department of Neurology, School of Medicine and Biomedical Sciences, University at Buffalo, State University of New York, Buffalo, NY, USA

Department of Psychiatry, School of Medicine and Biomedical Sciences, University at Buffalo, State University of New York, Buffalo, NY, USA

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### ABSTRACT

**Purpose:** Determine if a recently validated online survey of negative work events can predict future job loss among multiple sclerosis (MS) patients.

**Method:** Evaluated were 284 employed individuals (63 healthy controls, 221 MS patients), every three months, using an online vocational monitoring tool. Job loss rates in MS patients were compared with the healthy controls. Survey responses from MS patients suffering job loss ( $n = 23$ ) were then compared to those maintaining employment. Analyses focused on the frequency of negative work events.

**Results:** While 23 (10%) of MS patients lost their job after baseline, there was no job loss among the healthy controls. Compared to stably employed patients, those suffering job loss had been diagnosed with MS later in life, were more likely to report a progressive disease course, and had greater physical disability as measured by the Patient Derived Disease Steps (PDDS). Declining patients were also more likely to report negative work events within three months of job loss (e.g., verbal criticism for errors or removal of responsibilities). Stepwise logistic regression predicting MS job loss retained the PDDS, age at diagnosis, years working for employer and reporting a negative work event.

**Conclusions:** The results show that physical disability and patient reported risk factors for job loss can be monitored using an online survey tool. The tool can trigger clinical assessments to help prevent unemployment and assist patients in procuring disability benefits.

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### 1. Introduction

Diagnosis of multiple sclerosis (MS) is common in mid-life, often halting a person's career in the prime of their profession [1]. One study estimated that half of MS patients become unemployed within just five years of diagnosis [2]. MS unemployment is associated with reduced social engagement, poor self-efficacy and low quality of life [3]. In response, the MS community has called for increased guidance from clinicians regarding the risk of job loss among employed patients and how best to protect patients confronted with the threat of job termination [4,5].

Identification of clinical risk factors for unemployment would seem to be an important first step to intervene on behalf of the work-challenged MS patient. Cross-sectional studies show that fatigue, cognitive dysfunction, depression and impaired mobility are all associated with unemployment [6–18]. The few longitudinal studies of MS patients transitioning from employed to unemployed status have shown that reduction in

cognition and motor functioning are critical factors [19,20]. These studies distinguished fully employed from disabled patients, and did not examine ways to prevent job loss in employed patients reporting work problems. In this paper we endeavor to discover real life signals in the employed patient that indicate impending job termination.

Toward that end we have proposed that increases in work problems preceding job loss can be detected using online surveys. We have utilized the Buffalo Vocational Monitoring Survey (BVMS) as a means of characterizing work-challenged patients, identifying patients for intervention and referring patients to appropriate vocational and legal services. Our pilot study [10] demonstrated that MS patients who report negative work events perform worse on cognitive and ambulatory measures. Interestingly, despite the correlation between cognitive impairment and negative work events, disclosure status at work was not related to cognition [9], suggesting that patients need help navigating cognitive impairments in the workplace.

Our previous studies were cross-sectional in design, and did not address the predictive validity of a repeatable, online monitoring approach. In the present study we studied the incidence of job loss among employed MS patients and healthy controls (HCs). We then quantified negative work events in employed MS patients and assessed if these events are

<sup>\*</sup> Corresponding author at: Department of Neurology, Buffalo General Hospital, Suite E2, 100 High Street, Buffalo, NY 14203, USA.

E-mail address: [benedict@buffalo.edu](mailto:benedict@buffalo.edu) (R.H.B. Benedict).

more prevalent prior to job loss. Lastly, in order to develop future intervention perspectives, a secondary analysis was performed on accommodations before job loss. All analyses compared patients with deteriorating employment status (DES) and patients with stable employment status (SES). We hypothesized that negative work events are elevated in patients with deteriorating employment, signal the need for clinical/vocational intervention.

## 2. Methods

### 2.1. Research design

Enrollment in the Vocational Monitoring study was ongoing from 2012 to 2014. Participants were prompted via email to take the BVMS every three months, providing online consent for research participation. Monitoring duration varied among participants depending on enrollment date and when analysis was conducted [9,10]. Time course and duration for subject monitoring is presented in Fig. 1.

Employed MS patients were not compensated at the initial survey assessment as participation included clinical consultation and referral to vocational services if needed. One year from initial enrollment, patients were given additional monetary compensation to encourage continued monitoring. Employed healthy controls were compensated for their first survey response and their response one year from first assessment.

### 2.2. Sample procedures

Recruitment was conducted via flyers, advertisements on social media platforms, MS advocacy groups, and through the University at Buffalo Neurology clinic at Buffalo General Hospital. Healthy controls were similarly recruited via advertisements and also through families of participating MS patients. Patients responded from many different regions of the United States, although most were residents in the greater Buffalo metropolitan region. Subjects indicated diagnosis of MS via a yes/no question on the online survey with 118 (47%) having a confirmed MS diagnosis from the University at Buffalo Neurology clinic. Of the local patients, there were no cases where the reported MS diagnosis was not confirmed by a clinical assessment. Of those patients, 75 (63.6%) were diagnosed with Relapsing Remitting disease course and the remaining 43 (36.3%) were diagnosed with another disease course

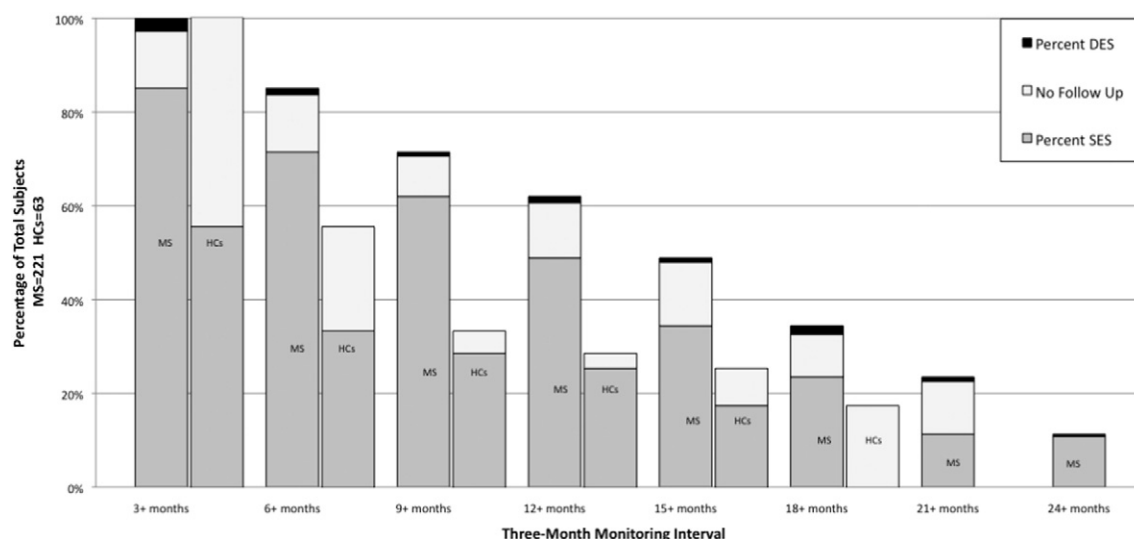
(Secondary Progressive, Clinically Isolated Syndrome, etc.). All participants provided consent as approved by the Health Sciences Institutional Review Board of the University at Buffalo.

Participants were excluded from analysis if they reported self-employment, working less than 10h per week, or retirement status. All were free of any neurological or psychiatric disorder other than MS, history of developmental delay or learning disability, and substance abuse. The final sample included 221 MS patients and 63 healthy controls (HCs). All subjects completed the survey at least twice, comprising at least three months of monitoring to determine job stability (Median = 12) (Range = 2.5–28 months). During monitoring, 23 MS patients reported job loss, constituting the Deteriorated Employment Status (DES) group. The 198 patients who continued to maintain employment were labeled the Stable Employment Status (SES) patient group. During comparative analyses, the last available time point before unemployment among DES patients was compared to the first available survey time point among SES patients.

### 2.3. Buffalo Vocational Monitoring Survey

The BVMS comprises four sections: (i) demographic questions, (ii) disease characteristics, (iii) descriptive employment information, and (iv) negative work events and accommodations. Demographic questions include gender, date of birth, and education. Disease characteristics incorporate questions regarding disease course, date of diagnosis and two surveys of self-reported disability: the Multiple Sclerosis Neuropsychological Questionnaire (MSNQ) [21–23] and the Patient Determined Disease Steps (PDDS) [24]. The MSNQ is a self-report survey for cognitive disability in which patients rate themselves on 15 questions concerning how often cognitive disturbances occur. The PDDS is a self-assessment tool in which patients rate themselves on a 0–9 scale of physical disability (9 being bedridden). Employment information includes annual income, number of hours worked per week, job title, disclosure status, and number of years working for the current employer.

All participants are asked to respond 'yes' or 'no' to the following questions regarding negative work events related to poor performance or mistakes at work over the last three months: (i) *verbal criticism for errors* (from a supervisor or co-worker), (ii) *a decrease in work hours*, (iii) *removal of responsibilities*, (iv) *formal discipline*, (v) *mandated additional support or training* and (vi) *asked to work additional hours to complete duties*. Although reported negative work events rely on patient



**Fig. 1.** Time course of the research design and attrition. DES = Deteriorated Employment Status, SES = Stable Employment Status. The first two columns show that 100% of the subjects were monitored at baseline and three months. Within the same column, 3% of the MS patients subsequently became unemployed at the next timepoint and 12% were lost to follow-up. Among the HCs monitored at baseline and three months, about 40% were lost to follow-up. The next two columns show what transpired for subjects remaining in the study at 6 months. For example, 28% of HCs were lost to follow-up. Subsequent columns follow the same formatting. The data highlight two observations. First, throughout, roughly 3% of patients lost employment at each time point. Second, none of the HCs became unemployed.

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