

Disease and Demographic Characteristics Associated with Unemployment Among Working-Age Adults with Multiple Sclerosis

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*Previous studies of employment in people with multiple sclerosis (MS) have been inconsistent in identifying associated factors, and few have examined the role of secondary health conditions. The goal of this study was to examine the association of these health conditions, including pain, fatigue, depression, sleep problems, anxiety, and incontinence, with employment status in individuals with MS. Data were collected using a cross-sectional self-report survey of 1271 people with MS, of whom 1124 were between the ages of 18 and 65 years and provided employment information. Self-report of employment status was used as an outcome variable for multivariate logistic regression. In total, 40.4% (n = 454) of surveyed individuals were employed half-time or more. Variables significantly associated with unemployment in the multivariate model were severity of disease (as measured by Expanded Disability Status Scale score), difficulties in thinking, female sex, increased age, and increased duration of MS. The symptoms of fatigue, pain, depression, and anxiety were not significantly associated with employment status in this sample. The combined impact of cognitive changes and overall severity of mobility impairment significantly influenced employment status in this community sample. Future longitudinal studies are needed to better elucidate the circumstances surrounding changes in employment status and identify points at which vocational rehabilitation interventions might be most effective. *Int J MS Care.* 2009;11:137–143.*

Although approximately 90% of individuals who have been diagnosed with multiple sclerosis (MS) were employed prior to their diagnosis,¹ only 20% to 40% remain in the workplace 5 years after the diagnosis.^{2,3} Many people with MS who are unemployed report a desire to return to work.¹ Because MS typically affects individuals in their prime employment years, unemployment can cause significant stress through loss of professional identity as well as financial hardship. Employment status has been linked to overall quality of life in people with MS as well as their caregivers.⁴ Unemployment may also bring a loss of health insurance coverage, resulting in reduced access to and continuity of health care.

Despite the high prevalence of unemployment among people with MS and the major impact it has on their lives, little is known about the interaction among variables that contribute to unemployment, maintaining employment, or returning to employment. In a recent Cochrane review, we identified only one randomized controlled trial (RCT) of vocational rehabilitation interventions and one other noncontrolled intervention study, although no synthesis of other non-RCT evidence was offered.⁵ In previous research, factors related to unemployment have been found to include level of disability (generally measured by the Expanded Disability Status Scale [EDSS]),^{1,6,7} age,^{1,2,8,9} cognitive functioning,⁸⁻¹⁰ education level,^{7,9,11,12} disease subtype,^{2,13} disease duration,^{2,8} and gender.¹ In one of the larger studies (N = 1310) on employment and MS, Roessler et al.¹⁴ evaluated the relationship of persistence of symptoms, severity of symptoms, educational attainment, affective symp-

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toms (yes/no), and cognitive symptoms (yes/no) with the categorical outcome variable, employed/not employed, and found that persistence and severity of symptoms, education, and presence of cognitive symptoms were related to employment status. In general, however, study findings have been inconsistent, with little examination of the role of multiple secondary health factors and conditions on employment. Perhaps most importantly, with the exception of the work of Roessler et al.,¹⁴ studies to date have been conducted with relatively small samples, limiting the generalizability of the results and the ability to examine multiple predictors of unemployment in a comprehensive or multivariate model.

Secondary health conditions may play a significant role in employment in MS. For example, in previous studies fatigue has been associated with diminished work performance and ability,^{15,16} while mood disturbance has been found to be higher among those currently working.¹⁶ Other secondary conditions that may be relevant to employment such as pain, depression, and anxiety have not been studied. The goal of this study was to examine the role of secondary conditions such as pain, fatigue, depression, and anxiety in a multivariate model with other hypothesized employment predictors (eg, age, sex, EDSS score, and education) to determine the relative association of these factors with employment status in people with MS.

Methods

Participants

Study participants were recruited through the Greater Washington Chapter of the National Multiple Sclerosis Society (NMSS), which serves 23 counties in Washington State. Letters of invitation were sent to 7806 people from the NMSS mailing list who were classified as having MS. Of the 1629 people who responded, 1597 were eligible for and indicated interest in participation. Eligible individuals were required to have a definitive diagnosis of MS and be at least 18 years of age. Eligible individuals were either mailed a self-report paper questionnaire (n = 1368) or directed to an online version of the same questionnaire (n = 229). Reminder letters were sent to nonresponders who received paper questionnaires between 3 and 6 weeks after the survey was mailed. A subset of individuals also received a reminder telephone call, but this procedure was discontinued once recruitment goals had been met. In total, 1271 individuals

completed a survey at least partially, and paper questionnaire responders with missing data were telephoned up to four times to collect the missing information. Because this study examined employment in working-age individuals, we further restricted our inclusion population to individuals between the ages of 18 and 65 years. Of the 1271 individuals who returned questionnaires, 1125 met this criterion and were therefore included in the analyses.

To assess the degree to which the total sample of respondents (n = 1271) was representative of the larger original recruitment population, a second anonymous one-page survey of demographics was sent to individuals on the NMSS mailing list. The goal was to examine potential recruitment bias and reasons for nonresponse to the initial solicitation. Efforts were made to remove all responders to the original survey from this second anonymous survey mailing. Additional information on nonresponders was not available, as letters of invitation were sent by the NMSS and study investigators did not have access to the mailing list. A total of 1046 individuals responded to the second anonymous survey. The responses indicated that some individuals on the mailing list did not have MS despite the NMSS classification (13%) or did not remember the initial survey invitation (34%). On average, the individuals who responded to the initial study survey were slightly younger, were more educated, and had a shorter mean disease duration than those who responded to the second anonymous questionnaire. All paper questionnaire respondents provided written consent to participate in the study at the time of survey completion, and online respondents indicated their consent electronically. All study procedures were approved by the human subjects division of the University of Washington.

Measures

The self-report survey questionnaire contained a variety of items on demographic, psychosocial, and functional or disease-specific characteristics.

Demographics and Disease-Specific Measures

Questions about ethnicity, education, gender, age, marital status, disease duration (ie, time since diagnosis), and mobility were included in the survey. Mobility was assessed using the mobility section of the self-administered version of the EDSS.¹⁷ Mobility scores were categorized into three groups: minimal (0–4.0), intermediate (4.5–6.5), and advanced (7.0–9.5) impairment. Individuals in the minimal group could walk without assistance

or rest for more than 500 m. Individuals in the intermediate group were limited by their disability in daily activities, and individuals in the advanced group were restricted to wheelchairs. Disease subtype was assessed in this sample using an instrument containing graphic images with associated text that allowed for classification of individuals into the four MS subtypes: relapsing-remitting, secondary progressive, primary progressive, and progressive relapsing.¹⁸

Symptom and Psychosocial Measures

Depressive symptoms were assessed using a short form of the Center for Epidemiological Studies Depression Scale (CES-D). This is a 10-item, self-rating scale developed to screen for depressive symptoms; its summary score has been shown to have adequate reliability and validity.¹⁹⁻²¹ In order to assess pain levels, individuals were asked to rate their average pain intensity over the past week on a numerical rating scale from 0 to 10. This scale is part of the Brief Pain Inventory (BPI) developed by Von Korff et al.²²; it has been widely used in research on many kinds of disabilities, including MS, and has been recommended for measuring pain in clinical trials.²³ Both physical and cognitive fatigue were assessed using the Modified Fatigue Impact Scale (MFIS).²⁴ The MFIS is an appropriate measure for assessing fatigue in individuals with MS when limited time is available and is one of the few scales that allow for separate assessment of physical and cognitive fatigue.^{24,25} The overall MFIS uses a subset of 21 items from the Fatigue Impact Scale (FIS),²⁶ 9 of which are summed to generate a physical fatigue score and 10 to generate a cognitive fatigue score.

To measure anxiety, the seven-item anxiety subscale of the Hospital Anxiety and Depression Scale (HADS) was included in the survey. The HADS was developed for use with hospital outpatients²⁷ and has been shown to be reliable, valid, and sensitive to change in many disability populations.²⁸ Information on sleep was collected using the Medical Outcomes Study Sleep (MOSS) measure,²⁹ and the Sleep Problems Index nine-item subscale of the MOSS, a measure of overall sleep problems, was specifically used as a predictor in this study. The MOSS measure has been validated in a large population of individuals with chronic diseases (hypertension, diabetes, congestive heart failure, recent myocardial infarction, and depression) and individuals from the general population selected through random-digit dialing.²⁹⁻³¹ Difficulties with cognitive function were assessed by asking individuals to

indicate on a 5-point Likert scale how much of a problem the symptom “problems thinking” was for them. For the regression analysis, individuals were categorized into three groups: thinking was “not at all” or “a little bit” of a problem, “somewhat” of a problem, or “quite a bit” or “very much” of a problem. This item was part of a larger scale we developed asking about the severity of 16 different MS-specific symptoms. In a previous study, this item was shown to be predictive of use of assistive technology.³² Problems with bowel or bladder function were also assessed on the same symptoms scale as problems in thinking, with individuals grouped into the same three categories as for thinking based on how much of a problem bowel or bladder issues were for them.

Employment

All participants were asked to report on their current employment status. Individuals were asked to indicate whether they were 1) employed less than 20 hours per week, 2) employed 20 or more hours per week, 3) unemployed, 4) a full-time homemaker, 5) attending school or vocational training (full- or part-time), or 6) retired. The actual number of hours of paid employment per week was also requested. Individuals were considered “employed” for purposes of the analyses if they endorsed option 2, “employed 20 or more hours per week,” or if they reported 20 or more hours of paid employment per week. This distinction was arrived at empirically, as during initial data inspection, it was observed that virtually all respondents who were employed worked either more than 20 hours per week or less than 3 hours per week, and we determined that from a qualitative perspective (eg, limited engagement, limited remuneration, lack of benefits) it was best to treat the latter as the equivalent of being unemployed. This is not to suggest that working several hours per week does not contribute to quality of life, but this level of employment is less likely to contribute to financial well-being and to have associated health-care benefits.

Analysis

Descriptive statistics were generated to characterize the study sample (Table 1). Logistic regression modeling was used to identify factors significantly associated with current gross underemployment or unemployment (employment less than 20 hours per week). Variables of interest included as candidates for the multivariate model were sex, age, disease duration, education level, disability level (EDSS score), type of MS, depression, pain, cogni-

Table 1. Demographic and disease characteristics of a community sample of individuals aged 18 to 65 with multiple sclerosis (N = 1125)

Variable	Value
Age, y	48.6 ± 9.9
Duration of disease, y	12 ± 9.0
Sex	
Female	909 (80.8)
Male	216 (19.2)
Race ^a	
White	1094 (97.2)
Native American or Alaska native	27 (2.4)
Asian	12 (1.1)
African American	21 (1.9)
Education completed	
< High school	16 (1.4)
High school/GED	137 (12.2)
Vocational/some college	429 (38.1)
Bachelor's degree	344 (30.6)
Professional/graduate	199 (17.7)
Employment status (n = 1124) ^a	
Employed ≥20 h/wk	454 (40.4)
Employed <20 h/wk	68 (6.0)
Unemployed	389 (34.6)
Retired	286 (25.4)
Homemaker	140 (12.5)
Student	30 (2.7)
Married (n = 1123)	
Married/live with significant other	793 (70.6)
Separated/divorced	199 (17.7)
Never married	109 (9.7)
Widowed	22 (2.0)
Course of disease (n = 1088)	
Relapsing-remitting	660 (60.7)
Secondary progressive	221 (20.3)
Primary progressive	118 (10.8)
Progressive relapsing	89 (8.2)
Level of disability (EDSS score) (n = 1116)	
Low (≤4.0)	382 (34.2)
Intermediate (4.5–6.5)	531 (47.6)
Advanced (7.0–9.5)	203 (18.2)

Abbreviations: EDSS, Expanded Disability Status Scale; GED, general equivalency diploma; SD, standard deviation.

Note: Values are given as No. (%) except for age and duration of disease, which are given as mean ± SD.

^aPercentages may sum to more than 100% because individuals were allowed to choose multiple answers.

tive fatigue, physical fatigue, sleep problems, anxiety, problems in thinking, and problems with bowel or bladder function. All variables were hypothesized a priori to potentially influence employment in this population. Age and disease duration were included as continuous

variables and sex as a categorical variable with males as the reference group. For more relevant interpretation, odds ratios (ORs) for age and disease duration are presented in terms of 10-year increments (Table 2). Education was coded into five ordered categories for the analysis, with the reference group as vocational training or some college education. Course of disease was included as a categorical variable, with relapsing-remitting disease course as the reference group for all other disease courses. Disability (EDSS score) was categorized as low, intermediate, or advanced, with low as the reference category. Pain, depression, cognitive fatigue, physical fatigue, sleep problems, and anxiety were all included as continuous variables, with scores generated as intended by the original scale authors. Pain was rated on a scale from 0 to 10, depression from 0 to 27, cognitive fatigue from 0 to 40, physical fatigue from 0 to 36, sleep problems from 0 to 100, and anxiety from 0 to 21. Difficulties in thinking or problems with bowel or bladder function were coded into three categories as described previously, with little or no difficulties as the reference group. All variables that were statistically significant at the .05 level according to a two-sided Wald test were considered to be associated with underemployment or unemployment. Prevalence ORs with 95% confidence intervals (CIs) were calculated for all significant variables. The model fit was tenable. Statistical analyses were performed using Stata Statistical Software, version 9.2 (StataCorp, College Station, TX).

Once modeling was completed, additional calculations were performed of percentage of people employed 20 or more hours per week by level of disease severity (EDSS score) and by category of difficulties in thinking (Fig. 1).

Results

In total, 1125 individuals between the ages of 18 and 65 responded to the survey, of whom 1124 provided information about employment status. Of these, 454 (40.4%) were employed half-time (20 hours/week) or more. Four hundred sixty-six (41.5%) individuals reported that they had retired early because of problems associated with their MS or were unemployed because of disability. One hundred forty (12.5%) reported that they were full-time homemakers, although only 8.5% endorsed being a homemaker without endorsement of unemployment because of disability. The majority of survey respondents were women (81%), white (97%), and married (71%) and had relapsing-remitting disease

Table 2. Multivariate logistic regression model of variables associated with underemployment or unemployment (<20 h/wk paid employment) in individuals aged 18 to 65 with multiple sclerosis in Washington State

Characteristic	χ^2	P	OR	95% CI
Severity of multiple sclerosis (EDSS score)				
Intermediate (4.5–6.5)	49.80	<.001	2.89	2.15–3.89
Advanced (7.0–9.5)	76.90	<.001	12.3	7.01–21.55
Difficulties in thinking				
Somewhat of a problem	4.04	.045	1.4	1.01–1.93
Quite a bit or very much of a problem	25.60	<.001	2.58	1.79–3.71
Female sex	3.96	.046	1.43	1.01–2.03
Age ^a	12.50	<.001	1.32	1.13–1.55
Duration of disease ^a	17.80	<.001	1.52	1.25–1.85

Abbreviations: CI, confidence interval; EDSS, Expanded Disability Status Scale; OR, odds ratio.

^aIncluded as continuous variable; OR presented in terms of 10-year increments.

(61%). The mean age of the sample was 48.6 years, and the mean disease duration was 12 years (Table 1).

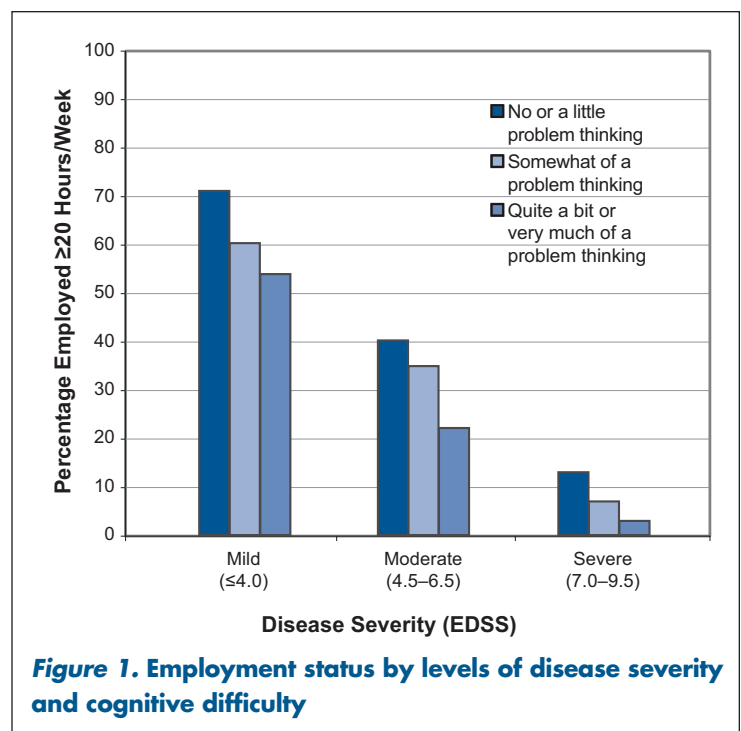
Through multivariate logistic regression, 5 of the 14 variables investigated were identified as being significantly associated with employment status: age, sex, duration of disease, severity of disease (EDSS score), and difficulties in thinking. Severity of mobility impairment, as measured by the EDSS, was the most significant factor, with odds of underemployment or unemployment 12 times higher for those with advanced disability and 2.9 times higher for those with intermediate disability as compared with those with minimal disability. The next most significant factor was reported difficulties in thinking, with the odds of unemployment being 2.6 times higher for those who reported quite a bit or very much of a problem compared with those who reported no or a little problem. Female sex, increased age, and longer duration of disease were all associated with increased odds of unemployment as well.

Further exploration of employment status by EDSS score and category of difficulty in thinking indicated that 66% of those with mild mobility impairment were employed, compared with 40% and 9% of those with moderate or severe mobility impairment, respectively. In those with no or a little difficulty in thinking, 49% were employed, compared with 38% and 24% of those with somewhat or quite a bit of a problem in thinking, respectively. Taken together, only 3% of those with severe mobility limitations and quite a bit of a problem in thinking were employed, compared with 71% of those

with mild mobility limitations and no or a little problem in thinking (Fig. 1).

Conclusions

Our survey and other recent work indicate that employment rates among people with MS have risen from 28% to 30% 20 years ago³ to about 40% today within this group. This improvement may be explained by the availability of newer, more effective medications and other symptom-ameliorating strategies. Clearly, however, employment rates for people with MS remain low, with unemployment potentially having a major negative impact on patients' quality of life.



The results of this study are generally consistent with previous studies suggesting that EDSS score, cognitive changes, sex, and age are important predictors of employment in people with MS. The combined impact of cognitive changes and overall severity of mobility impairment seems to be the best predictor of unemployment (or gross underemployment). In particular, our results are similar to those of Roessler et al.¹⁴ with respect to the impact of cognitive changes and disease burden. Our study differs in that we asked detailed questions using standardized instruments with respect to secondary conditions and examined employment as continuous initially, collapsing it for the final analysis. We had speculated that the burden of secondary conditions such as pain and fatigue would be related to employment status, but that was not borne out by the data. These variables may be found to contribute to change in status in longitudinal studies, and the cross-sectional data reported above constitute the first data-collection point for a longitudinal study that we are conducting. Alternatively, the burden of secondary conditions may not contribute to employment outcomes per se but may be related to perceived quality of life associated with employment status. These findings are not totally inconsistent with those of the multisite Project Alliance vocational rehabilitation intervention study, in which physical fatigue and cognitive limitations were self-reported as the clients' biggest obstacles to maintaining work.³³ These were clients who actually sought job accommodation consultation, however.

The large sample size that allowed us to perform multivariate analyses distinguishes this study from previous work. The findings allow better profiling of unemployment risk as related to cognitive concerns and physical impairment. Our findings are inconsistent with those of several recent studies. For example, in a small study (N = 50), Smith and Arnett¹⁶ found that age, gender, duration, and IQ did not predict employment in people with MS. Phillips and Stuijbergen¹¹ found that education was a significant predictor of unemployment. The overall educational level in our sample is higher with less variability than that in the sample of Phillips and Stuijbergen and thus may have less predictive value. A significant limitation of our study is our lower response rate and the discrepancy between responders and nonresponders in terms of age, education, and disease duration. It is possible that the sample of responders is employed at a higher rate than the actual population of people with MS and

that their employment status may be less affected by secondary conditions because they may have a slightly lower burden of symptoms.

Future research on employment and MS should include longitudinal studies with well-established baseline measures in order to better elucidate the circumstances surrounding changes in employment status and time points at which vocational rehabilitation interventions may be most economically and effectively deployed. From the Project Alliance study,³³ it is apparent that job site accommodation may help to preserve employment, especially when the client allows the vocational rehabilitation consultant to access the employer directly. Future research is needed to clarify for whom and at what times self-management and self-advocacy efforts are effective and when these may need to be combined with more comprehensive and formal vocational rehabilitation interventions in order to preserve employment in this population. In addition, future studies should investigate the interaction between private and federal disability and health insurance subsidies and employment status. Currently, it appears that adults with MS are moving toward long-term disability status (eg, as indicated by applications for long-term disability benefits) at a much faster rate than populations with general or other neurologic disability.³⁴ This may reflect a cascade of interacting effects related to disease progression, lack of accommodation in the workplace, loss of employment-related health-care benefits, and the disability benefit systems as they currently exist. □

Practice Points

- Employment rates for people with MS remain low, and many people with MS who are unemployed would prefer to be working. Because employment status is linked to quality of life in people with MS, clinicians should determine their patients' current and desired employment situations.
- The combined impact of cognitive changes and overall severity of mobility impairment seems to be the best predictor of unemployment in the MS population.
- The findings reported here can help clinicians determine which patients will require vocational rehabilitation intervention in order to maintain employment and can be used to support the need for private and public disability subsidies.

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