

Short Term Predictors of Unemployment in Multiple Sclerosis Patients

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ABSTRACT: Background: Unemployment is common in people with multiple sclerosis (MS) and is associated with loss of income and impaired health related quality of life. This study determined variables associated with unemployment and risk factors for the development of unemployment in people with MS. **Methods:** Ninety-six patients who were under age 65 and participated in two previous studies to measure economic costs and health related quality of life in MS were included. The baseline employment rate and variables associated with unemployment at baseline were determined. The ability of these variables to predict unemployment over the next two and a half years was then evaluated. **Results:** At baseline 50.1% (50/96) of participants were employed. Two and a half years later only 40.6% (39/96) remained employed. This represents loss of employment for 22.0% (11/50) of those originally employed. Factors associated with unemployment at baseline included greater disability, progressive disease course, longer disease duration, and older age. Risk factors for loss of employment over the next 2.5 years included greater disability and older age. **Conclusions:** This study confirms the low employment rate among people with MS and confirms the association of several previously-reported factors with greater risk of unemployment. It is also the first study to confirm that some of these factors also increase the risk of future unemployment. People with MS who are over age 39 or have moderate disability and are still employed can now be identified as at risk for becoming unemployed over the next 2.5 years. They should be considered for interventions to maintain employment or to lessen the impact of unemployment.

RÉSUMÉ: Impact de la sclérose en plaques sur l'emploi: étude pilote pour identifier les facteurs qui prédisent à court terme le chômage. Contexte: Le chômage est fréquent chez les individus atteints de sclérose en plaques (SEP) et il est associé à une perte de revenu et à une diminution de la qualité de vie reliée à la santé (QVRS). Cette étude a identifié des variables associées au chômage et des facteurs de risque du chômage chez les individus atteints de SEP. **Méthodes:** Quatre-vingt-seize patients de moins de 65 ans, ayant participé à deux études antérieures sur les conséquences économiques et la QVRS dans la SEP, ont été inclus dans l'étude. Le taux d'emploi et les variables associées au chômage ont été déterminés au début de l'étude. On a évalué la capacité de ces variables à prédire le chômage éventuel au cours d'une période de deux ans et demie. **Résultats:** Au début de l'étude, 50,1% (50/96) des participants avaient un emploi. Deux ans et demi plus tard, seulement 40,6% (39/96) travaillaient encore, ce qui représente une perte d'emploi pour 22,0% (11/50) de ceux qui travaillaient au début de l'étude. Les facteurs associés au chômage au début de l'étude étaient: un degré plus élevé d'invalidité, une maladie progressive, une durée plus longue de la maladie et un âge plus élevé. Les facteurs de risque d'une perte d'emploi pendant les 2,5 années de l'étude étaient: un degré d'invalidité supérieur et un âge plus élevé. **Conclusions:** Cette étude confirme le faible taux d'emploi chez les individus atteints de SEP et l'association de plusieurs facteurs déjà identifiés avec un risque plus élevé de chômage. C'est également la première étude à confirmer que certains de ces facteurs augmentent également le risque de chômage subséquent. On peut dorénavant considérer que les individus atteints de SEP, qui ont plus de 39 ans ou qui ont une invalidité modérée et qui ont encore un emploi, sont à risque de devenir chômeurs dans les 2,5 prochaines années. On devrait envisager d'intervenir pour maintenir l'emploi ou pour diminuer l'impact du chômage éventuel.

Can. J. Neurol. Sci. 2003; 30: 137-142

Multiple sclerosis (MS) is the most common cause of neurologic disability among young Canadians.¹ It has a significant economic impact on people with the disease, their families, and society. Prior to the availability of expensive disease modifying therapies, the loss of employment income,

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RECEIVED AUGUST 13, 2002. ACCEPTED IN FINAL FORM DECEMBER 9, 2002.

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productivity and leisure time were estimated to account for up to 80% of the financial losses incurred by MS patients and their families.¹⁻³ Estimates of the economic costs of MS due to lost employment and productivity ranged from \$6,341 to over \$20,000 (Canadian dollars)¹⁻³ and the disease was reported to result in loss of greater than 90% of the yearly, premorbid income.⁴ Societal impact increases with MS prevalence and becomes particularly important in places like Canada where disease prevalence is high, ranging from 87-220 cases per 100,000 population.⁵⁻⁷

Multiple sclerosis may also limit job satisfaction. Compared to other disabled workers, MS patients have a diminished degree of satisfaction with their work.⁸ Conversely, loss of the ability to work may also reduce quality of life as unemployment and decreased household income are associated with decreased quality of life.⁸ Identification of factors associated with lost productivity and employment could allow the development of interventions to significantly benefit patients and society.

Several studies have examined the relationship between MS and employment.^{1,9-22} While all have described a rate of unemployment ranging from 22-80%, the true impact of MS on employment remains poorly characterized because the populations studied, the methods used, and the definition of employment, or unemployment, varied. There is no definitive definition of employment or unemployment as considerations vary with the population and the perspective taken. In addition, most studies lack a comparison group thus limiting estimates of the magnitude of the disease-specific association.

Many studies, however, have identified factors associated with unemployment in MS. Disease-related factors consistently associated with unemployment are greater degree of disability, longer disease duration and progressive course. Specific types of impairment, such as cognitive impairment, have also been associated with unemployment²³ although the specific variables evaluated varied from study to study. Demographic variables frequently associated with unemployment include older age and lower level of education. Finally, job specific and social factors are also important. Manual labor, private sector employment, and lack of accessible transportation to get to and from work have been associated with unemployment.

While many factors have been frequently associated with unemployment, none of these studies have determined if they are predictors of future unemployment, even over the short term. Therefore, in order to better develop and evaluate interventions to reduce unemployment, it is important to determine which factors are associated with unemployment risk. This paper reports the results of a prospective study to determine predictors of unemployment in people with MS.

METHODS

Patient population

Over a 15-month period in 1996 and 1997, 319 patients from two population-based MS clinics (Calgary and Nova Scotia) participated in a cross-sectional study examining the economic costs associated with MS. Stratified random sampling, from population-based clinic databases, was employed in an attempt to have equal representation from patients with varying degrees

of disability measured by the extended disability status scale (EDSS). Patients were recruited to one of four disability groups: EDSS 0-2.5, EDSS 3.0-5.5, EDSS 6.0-8.0 and EDSS 8.5-9.5. The aim was to recruit 50 patients at each disability level from each clinic but the smaller population in Nova Scotia limited the ability to recruit into some disability groups. Because employment was suspected to be biased by this recruitment problem only the Calgary participants were eligible for this analysis. The Calgary MS Clinic is the only source of neurologic care in the region so most people with MS have been seen at least once in the clinic. Patients seen only once had the same chance of recruitment as those who visit the clinic frequently. While a record of those who declined to participate was not kept, a small number of patients declined.

Employment status was obtained from an interview question that asked patients to choose their primary activity from a list of given options matching those used for the collection of Canadian census data. For the purposes of this analysis, a person was considered 'employed' if they were less than 65 years of age and selected their primary activity as 'working for pay or profit', 'caring for family', 'caring for family and working', or 'going to school'. Exploratory analysis also determined the impact of defining those 'caring for family' (homemakers) as either 'unemployed' or excluding them from the analysis. A person was considered unemployed if they selected 'short term disability', 'long term disability', 'looking for work', 'not working but not looking for work', or 'retired'.

Demographic and disease-specific data were also collected. Disability was measured and rated using the EDSS. Between August 1999 and March 2000, patients were recontacted and asked to participate in a study of health-related quality of life. The same employment question was repeated. For the purpose of this analysis, the Calgary participants in the initial study who were under age 65 were called the total sample. The subset who also participated in the second study at 2.5 years was called the study sample. Both studies were approved by the University of Calgary research ethics board.

Variables evaluated

Demographic data collected included age, sex, education, and marital status. Binary or categorical variables were created from continuous variables and due to the small sample size most categorical variables (as described in Table 1) were redefined by combining subgroups (as per Table 2). Age was arbitrarily defined as < 40 years old and ≥ 40 years old. Education status was arbitrarily defined by those who were high school graduates and those who were not. Marital status was defined as coupled (married or cohabiting) or not (divorced, never married, separated or widowed).

Disease-related variables included EDSS, MS course, and disease duration. Duration was defined as the time from the onset of definite symptoms to the time of baseline data collection. Categorical or binary variables were created for EDSS and disease course. The EDSS group was defined by the four groups originally used to stratify the participants: EDSS 0-2.5, EDSS 3.0-5.5, EDSS 6.0-8.0 and EDSS 8.5-9.5. The MS course was defined as relapsing remitting MS or progressive MS. The progressive group included patients with primary progressive MS, secondary progressive MS and progressive relapsing MS

Table 1: Comparison of disease and demographic characteristics of participants and nonparticipants

| Variable | Nonparticipants under age 65 | Participants under age 65 | p-value |
|---------------------------------|---------------------------------|------------------------------|-------------------|
| N | 82 | 96 | |
| Mean age (years) | 44.3 | 47.2 | NS ¹ |
| Age Group, N (%) | | | |
| • < 30 | 7 (8.5) | 4 (4.2) | NS ² |
| • 30-39 | 14 (17.1) | 18 (18.8) | |
| • 40-49 | 40 (48.8) | 37 (38.5) | |
| • 50 | 21 (25.6) | 37 (38.5) | |
| Sex, N (%) | | | |
| • Male | 26 (31.7) | 33 (34.4) | NS ² |
| • Female | 56 (68.3) | 63 (65.6) | |
| Median disease duration (years) | 16.4 | 14.8 | NS ³ |
| EDSS Group, N (%) | | | |
| • 0-2.5 | 18 (22.0) | 33 (34.4) | 0.02 ² |
| • 3.0-5.5 | 24 (29.3) | 29 (30.2) | |
| • 6.0-8.0 | 19 (23.2) | 25 (26.0) | |
| • 8.5-9.5 | 21 (25.6) | 9 (9.4) | |
| MS Course, N (%) | | | |
| • Relapsing remitting | 33 (41.3) | 43 (44.8) | NS ² |
| • Secondary progressive | 26 (32.5) | 27 (28.1) | |
| • Primary progressive | 16 (20.0) | 23 (24.0) | |
| • Progressive relapsing | 5 (6.2) | 3 (3.1) | |
| Education, N (%) | | | |
| • High school graduates | 74 (91.4) | 83 (86.5) | NS ² |
| Marital Status, N (%) | | | |
| • Married | 58 (70.7) | 64 (66.7) | NS ² |
| • Cohabiting | 0 (0) | 5 (5.0) | |
| • Divorced | 12 (14.6) | 13 (13.5) | |
| • Never married | 6 (7.3) | 11 (11.5) | |
| • Separated | 3 (3.7) | 2 (2.1) | |
| • Widowed | 3 (3.7) | 1 (1.0) | |
| Employment, N (%) | | | |
| • Employed | 33 (40.2) | 50 (52.1) | NS ² |
| • Unemployed | 49 (59.8) | 46 (47.9) | |

¹ Student's t-test, ² Fisher's exact test, ³ Wilcoxon rank-sum test
NS = not significant

Table 2: Factors associated with unemployment at baseline.

| | Employed N = 50 | Unemployed N = 46 | P value |
|--------------------------|--------------------|----------------------|---------|
| EDSS Group, N (%) | | | |
| • 0-2.5 | 30 (60.0) | 3 (6.5) | <0.001 |
| • 3.0-5.5 | 14 (28.0) | 15 (32.6) | |
| • 6.0-8.0 | 6 (12.0) | 19 (41.3) | |
| • 8.5-9.5 | 0 (0) | 9 (19.6) | |
| Disease Course, N (%) | | | |
| • Relapsing-remitting | 33 (66.0) | 10 (21.7) | <0.001 |
| • Progressive | 17 (34.0) | 36 (78.3) | |
| Disease Duration, N (%) | | | |
| • < 10 years | 23 (46.0) | 7 (15.2) | 0.001 |
| • 10-19.9 years | 17 (34.0) | 17 (37.0) | |
| • 20 years | 10 (20.0) | 22 (47.8) | |
| Age, N (%) | | | |
| • < 40 years | 20 (40.0) | 2 (4.4) | < 0.001 |
| • 40 years | 30 (60.0) | 44 (95.6) | |
| Sex, N (%) | | | |
| • Female | 30 (78.0) | 24 (52.2) | 0.010 |
| • Male | 11 (22.0) | 22 (47.8) | |
| Education, N (%) | | | |
| • No high school diploma | 6 (12.0) | 7 (15.2) | 0.768 |
| • High school diploma | 44 (88.0) | 39 (84.8) | |
| Marital Status, N (%) | | | |
| • Married or cohabiting | 38 (76.0) | 31 (67.4) | 0.373 |
| • Other status | 12 (24.0) | 15 (32.6) | |

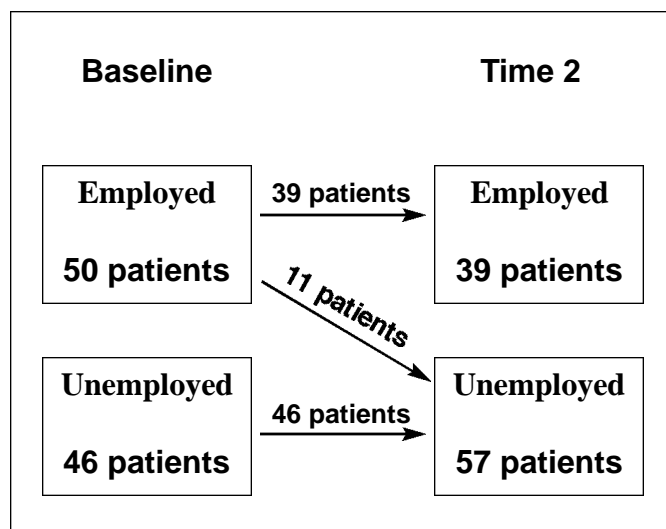


Figure: Employment groups

disease. Disease duration was arbitrarily defined as < 10 years, 10.0 – 19.9 years, and 20 years.

Statistical methods

The study sample was described and compared to the total sample. Associations between baseline variables and employment status were evaluated. Statistically significant variables were stratified by each of the other variables to explore for the presence of potential interactions or confounding at baseline. Only those employed at baseline were included in the analysis of predictors of unemployment 2.5 years later. Relative risk and 95% confidence intervals were then calculated. Significance was examined using Fisher's exact test with two-tailed significance set at the 0.05 level. Due to the small sample size and large number of significant variables, multivariate analysis was not done. Analysis was carried out using STATA 6.0 statistical software.

RESULTS

There were 196 participants in the initial study from the Calgary clinic; 178 were under age 65 and were therefore included in the total sample. The study sample comprised the 96 patients who were less than 65 years of age at study baseline and that participated in the 2.5 year study. The participants (n=96) and the nonparticipants (n=82) are described and compared in Table 1. The study sample did not differ from the total sample except it included a higher proportion of patients with less disability.

The mean age of patients in the study sample was 47.2 years with a range of 25-63 and a standard deviation of 9.0 years. Sixty-six percent were women, 71.7% were either married or cohabiting, and 86.5% were high school graduates. Median disease duration was 14.8 years, and ranged from 1-47 years. Disability ranged from EDSS 1.0-9.0. Thirty-three patients (34.4%) had EDSS scores of 0-2.5, 29 (30.2%) had scores of 3.0-5.5, 25 (26%) had scores of 6.0-8.0, and 9 (9.4%) had scores of 8.5-9.5. Forty-three (44.8%) had relapsing remitting MS, 27 (28.1%) had secondary progressive MS, 23 (24%) had primary progressive MS and three (3.1%) had progressive relapsing MS.

At baseline, 54.0% of patients (95/176) less than age 65 were unemployed. This did not differ between those that participated in the second data collection and those that did not. The proportion of participants (the study sample) that were unemployed was 47.9% (46/96) compared to 59.8% (49/82) in nonparticipants (p=NS). The oldest employed participant was 60 years of age. The study sample included 14 homemakers, all of whom were women, and two students. As in previous studies higher EDSS group, progressive course, longer disease duration, and older age were associated with a greater chance of being unemployed at baseline. Level of education and marital status were not (Table 2) associated with employment status. Male sex was associated with a greater chance of unemployment in the primary analysis, however, the subgroup of 30 'employed' women included all 14 of the homemakers. When homemakers were redefined as unemployed, or were excluded from the analysis, sex was no longer associated with employment status. When homemakers were considered unemployed or excluded from the analysis, the significance of other variables was

maintained. Stratified analysis did not reveal any interactions or confounding but the reduced size of each new subgroup limited the power of this testing.

The mean time between baseline and the second study was 2.55 years at which time 39/96 patients (40.6 %) were still employed. Eleven patients (11.5 %) from the initial sample of 96 became unemployed over the 2.5 years since baseline (Figure). This represents 22.0 % of the initially employed sample of 50 people. None of the patients initially defined as unemployed became truly employed but five people, including one male, now chose 'homemaker' as their primary employment activity. Two of these people previously chose 'long term disability', and three were previously working. In each case we still considered them to be unemployed. Five 'homemakers' at baseline changed their status to 'long term disability' and one person chose 'retired' despite being under age 65.

Risk factors for the development of unemployment included greater disability and older age. The relative risk of becoming unemployed was 17.5 times greater for those with EDSS scores >5.5 compared to those with EDSS scores <3.0 (95% CI 2.37-129.06, p = 0.0008). The RR was 7.5 for those with EDSS scores >5.5 when compared to those with EDSS <3.0 (95% CI 1.07-52.81, p = 0.018). The relative risk of becoming unemployed was 1.77 for those over age 39 compared to those 39 or less (95% CI 1.24-2.54, p = 0.033). Longer disease duration, disease course, sex, marital status and education were not significant predictors of unemployment.

DISCUSSION

The proportion of patients employed at baseline (52.1 %) and time two (40.6 %) was comparable to employment rates reported for people with MS but were much lower than the regional (Alberta) employment rate at the same time of 68.6%.²⁴ In comparison to the Alberta employment rate our study overestimates employment because we considered students and homemakers employed whereas they are not considered employed in the Alberta provincial employment figures. At baseline students and homemakers comprised 2% and 14% of our sample, respectively. Their exclusion would have dropped our employment rate at baseline to 33%; less than half the provincial rate. Because provincial unemployment rates focus on people capable of working but unable to find jobs, they are not useful for comparison with our clinic sample where many people are not capable of employment. Because Alberta has relatively high employment rates compared to other regions of Canada it is unlikely that employment rates for MS patients are better elsewhere in Canada. Interpretation of employment data would be improved if a comparable control group were available.

Factors associated with unemployment at baseline included increased disability, older age, progressive course, and longer disease duration. These associations have all been previously reported. The consistent association between increased disability and unemployment^{1,14,20} is not surprising as disability reduces an individual's ability to perform tasks, a natural requirement of employment. While the small sample size limited our ability to detect interactions and confounding there are hypothetical reasons that each of these factors may independently contribute to unemployment. Progressive course^{9,16,22} may influence

employment because without a stable level of ability it is hard to make accommodations in the workplace. Longer disease duration^{14,15} may be associated with accumulation of deficits not reflected in the EDSS. In addition, cognitive dysfunction which is more likely to be present in those with progressive disease and with longer disease duration, is known to affect employment.²³ Older age may be associated with unemployment because the chance of acquiring co-morbid disease increases with age and these co-morbidities may increase the impact of MS. Early retirement is also more likely at older ages. It may become a more appealing, or necessary, option in those with MS. Age, however, may also confound the interpretation of employment data in MS. In this study only 4 of 10 'retired' patients were over age 65 and only 2/41 patients over the age of 50 were gainfully employed.

The apparent association between male sex and unemployment, which had not previously been reported in MS, led to further evaluation of potential sources of bias. A systematic error, related to our definition of homemakers as employed, appears to have been responsible for this apparent association. Homemakers, who were no longer capable of carrying out their homemaking role, may have chosen this as their main employment activity because there was no better option available to them. In the total sample at baseline (n = 319), the proportion of people classified as 'working' decreased with disability but the proportion classified as homemakers (all women) did not change with level of disability. This put women at an apparent advantage with regards to the proportion that were able to, by definition, maintain employment. LaRocca¹³ defined homemakers as unemployed and reported an increased rate of unemployment in women. While we did not find female sex to be associated with unemployment when we reclassified homemakers as unemployed, our sample size was smaller and women's roles in the workforce may have evolved since LaRocca's study was published in 1985. Defining homemakers as employed therefore appears to overestimate their ability to undertake gainful employment. Conversely, defining women as unemployed seems to result in an underestimate. Future studies of employment should consider getting more detailed information regarding a homemaker's abilities to complete the tasks required in this role in order to determine if each individual is employed or not.

It was not surprising to find greater disability and older age to be short term predictors of unemployment because they have consistently been associated with unemployment. Our inability to confirm longer disease duration and progressive course as a risk factor may have been due to the limited sample size and short period of follow-up.

The major limitations of this study were the small sample size and the limits of using existing data. There may also have been selection bias. The small sample size limited the power to detect associations, predictors, interactions, and confounding effects. It also made multivariate analysis inappropriate. A larger sample size would be necessary to address these issues.

The use of existing data limits the analysis that can be done. Before leading to loss of employment, MS may influence or require a person to change their career, introduce modifications in their workplace, or modify their workload. Sometimes this leads to underemployment or partial employment. Therefore, employment is not a yes or no issue. The ability of an individual

to remain employed may also relate to their disease activity, other unmeasured effects of the disease, co-morbidity, the demands of their job and their employer, social support, and psychological factors. Use of existing data prevented us from addressing these issues but helped us identify these other factors as potentially influencing employment. This will help in the design of future research. To address this large number of variables, a large sample is required to provide adequate power to detect significant associations.

While the study sample was representative of the total sample with regards to variables measured, unrecognized selection bias cannot be excluded. Because the second data collection focused on evaluation of quality of life measures it is unlikely that patient interest in employment status was a factor in participation. This cannot be determined, however, as we do not know the employment status at the time of the second data collection, of those who chose not to participate.

Despite these limits this study is the first prospective study to identify predictors of unemployment in MS. Other prospective studies are required to confirm these findings, and larger studies will likely be needed to detect other determinants of unemployment. Identification of these predictors will allow those at risk to be targeted for intervention which may reduce either the risk or the impact of unemployment. While aging cannot be prevented, disease-modifying therapies that affect disability may also delay unemployment. Rehabilitation, counseling, workplace evaluations, vocational retraining, and directed financial planning may also be useful interventions.

ACKNOWLEDGEMENTS

This study was supported by the Multiple Sclerosis Society of Canada and AstraZeneca.

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