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Personal Income Before and After Diagnosis of Multiple Sclerosis

Erik Landfeldt, PhD^{1,2,*}, Anna Castelo-Branco, PhD¹, Axel Svedbom, MSc¹, Emil Löfroth, MSc³, Andrius Kavaliunas, PhD⁴, Jan Hillert, MD⁴

¹Mapi Group, Stockholm, Sweden; ²Institute of Environmental Medicine, Karolinska Institutet, Stockholm, Sweden;

³Novartis, Stockholm, Sweden; ⁴Department of Clinical Neuroscience, Karolinska Institutet, Stockholm, Sweden

ABSTRACT

Background: Multiple sclerosis (MS) is associated with serious morbidity and labor force absenteeism, but little is known of the long-term impact of the disease on personal income. **Objectives:** To assess long-term consequences of MS on personal salary and disposable income. **Methods:** Patients with MS in Sweden were identified in a nationwide, disease-specific register and matched with general population controls. We assessed mean annual personal gross salary and disposable income each year before and after index (i.e., the MS diagnosis date) using data from national registers. **Results:** The final sample consisted of 5,472 patients and 54,195 controls (mean age 39 years; 70% females). There was no significant difference in gross salary between patients and controls in any year within the pre-index period. In contrast, on average during follow-up post diagnosis, patients with MS had €5,130 less gross salary per year compared with controls, ranging from a loss of €2,430 the first year to €9,010 after

11 years. Within 10 years after index, 45% of patients had at least one record of zero gross salary, compared with 32% for controls. Mean annual disposable income was comparable between patients and controls across follow-up, with significant differences only at years 9 and 10 post-index. **Conclusions:** We show that many patients with MS in Sweden lose their ability to support for themselves financially but still have a relatively high disposable income because of social transfers. Our findings underscore the detrimental impact of MS on affected patients and the considerable economic burden of disease to society.

Keywords: cost of illness, longitudinal studies, multiple sclerosis, sick leave, Social Security, Sweden.

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Introduction

Multiple sclerosis (MS) is a chronic demyelinating disease of the central nervous system [1]. Depending on clinical phenotype and severity, manifestations of MS are highly variable and often unpredictable, ranging from mild infrequent relapses with limited impact on functional ability to rapidly accumulating disability, loss of independent ambulation, and extensive cognitive impairment [2,3]. Most patients are diagnosed in early adult life, between age 20 and 40 years, and the disease is about twice as prevalent among women as among men [1,4].

Because of the disability and morbidity associated with the condition, MS has serious adverse effects on the day-to-day life of many patients, including their ability to work. In fact, we have

recently shown that nearly 4 out of 10 patients in Sweden are now fully absent from the labor force within one decade of diagnosis, more than 20 years before the official retirement age [5]. Thus, depending on national welfare redistribution systems, patients with MS are at risk of losing an important component of their financial security, in particular in more advanced stages of the disease.

Several studies have investigated the impact of MS on income [6–9], but no study has, to our knowledge, conducted a longitudinal analysis encompassing several years both before and after diagnosis of the disease. The objective of this study was to describe the long-term association between MS and income in a nationwide sample of patients with MS and matched controls from the Swedish general population.

Conflicts of interest: E. Landfeldt, A. Castelo-Branco, and A. Svedbom are consultants to Novartis through their employment at Mapi Group. E. Löfroth is an employee and shareholder of Novartis. A. Kavaliunas reports no conflicts of interest. J. Hillert has received honoraria for serving on advisory boards for BiogenIdec and Novartis; has received speaker's fees from BiogenIdec, Merck-Serono, Bayer-Schering, Teva, and Sanofi-Aventis; and has served as investigator for projects sponsored by, or received unrestricted research support from, BiogenIdec, Merck-Serono, Teva, Novartis, and Bayer-Schering.

* Address correspondence to: Erik Landfeldt, Institute of Environmental Medicine, Karolinska Institutet, Nobels väg 13, Stockholm SE-17177, Sweden.

E-mail: [E-mail: erik.landfeldt@ki.se](mailto:erik.landfeldt@ki.se).

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Methods

Study Design and Population

This retrospective register study was based on a cohort of patients with MS and Swedish general population controls for which details and results have been previously reported [5]. In summary, our sample of patients was identified through a nationwide disease-specific registry, the Swedish Multiple Sclerosis Registry [10]. To ensure sufficient follow-up prediagnosis given data availability, we excluded patients with a diagnosis before 2001 as well as those younger than 18 years and those older than 65 years at diagnosis (i.e., the official retirement age in Sweden). We also excluded patients diagnosed after December 31, 2011, to allow for a minimum of one calendar year of follow-up and to avoid bias due to nonrandom censoring. To obtain a control group, we matched each patient with 10 individuals without MS from the general population on the basis of age, sex, and region of residency at diagnosis using data from the Swedish Total Population Register. Controls with less than one calendar year of follow-up (because of, e.g., emigration, death, or data availability) were excluded. Last, we coded the date of the MS diagnosis as the index date for patients and matched controls.

The main study outcomes were personal gross salary and disposable income measured using data extracted for each calendar year from 1994 through 2012 from the Swedish Social Insurance Agency's database, Micro Data for Analysis of the Social Insurance. As defined by the Swedish National Mediation Office of the Ministry of Employment [11], gross salary comprises compensation from work, whereas disposable income comprises gross salary, transfers (e.g., sickness benefit, early retirement pension, and disability allowance), and capital gains. For presentation of the results, income data were converted from Swedish krona to euros using the exchange rate SEK 1 = €0.104071.

We extracted patient-level inpatient comorbidity data (as specified in the Charlson comorbidity index) 5 years before the index date from the Swedish National Patient Register using the *International Classification of Diseases, Tenth Revision*, diagnosis codes. In accordance with our previous work [5], we also measured a set of MS-related comorbidities hypothesized to be related to work ability and loss of income (depression/anxiety [12], pain [13], insomnia [14], and bacterial infection [15]) each calendar year post-index using inpatient and outpatient data from the Swedish National Patient Register and data for filled prescriptions from the Swedish Prescribed Drug Register (available from July 1, 2005). Data on age, sex, migration, marital status, and education level were extracted from the Swedish Total Population Register and the Longitudinal Integration Database for Health Insurance and Labor Market Studies. Dates of death were extracted from the Swedish Cause of Death Register.

The study was approved by the Regional Ethical Review Board in Stockholm, Sweden.

Statistical Analysis

We assessed mean annual gross salary and mean annual disposable income for each calendar year pre-index and post-index. Individuals were censored post-index for emigration, reaching an age of 65 years (the official age of retirement in Sweden), and death, and before index for age 18 years, immigration, and data availability (January 1, 1994).

We fitted two linear mixed-effects regression models to the longitudinal data to explore determinants of gross salary among patients with MS by sex. Random effects were specified at the

patient level, as well as for each year of follow-up (i.e., we modeled a unique intercept for each patient and a unique slope for each year of follow-up). To control for fixed effects, the models were adjusted for age, university education, marital status, Expanded Disability Status Scale (EDSS) score, comorbidities, and calendar year.

To further investigate the impact of MS on gross salary, we analyzed time to zero gross salary using survival analysis. Specifically, Kaplan-Meier failure functions with zero income as failure event were estimated, with time measured from index to first occurrence of zero gross income or censoring (because of emigration, age 65 years, or death). We also fitted a Cox proportional hazards model, specified to include age, marital status, university education, and prevalent comorbidities at index, to our survival data to investigate the adjusted risk increase of having zero income (first occurrence) in patients with MS compared with controls.

We compared demographic and disease characteristics and income data between patients and controls using the Welch *t* test and the Pearson χ^2 test. All analyses were conducted using Stata 14 (StataCorp, College Station, TX).

Results

The final cohort consisted of 5,472 patients who had been diagnosed with MS between January 1, 2002, and December 31, 2011, and 54,195 matched controls from the Swedish general population (Table 1). During follow-up (i.e., 1994 through 2012), the study population contributed a total of 994,356 years of observation time.

Gross Salary Before and After Diagnosis of MS

Estimates of the mean annual gross salary for patients with MS and general population controls, stratified by year pre-index and post-index, are presented in Figure 1. There was no significant difference between patients and controls in any year within the pre-index period ($P > 0.162$ for all comparisons). In contrast, on average, during follow-up post-index, patients with MS had €5,130 less gross salary per year compared with controls, ranging from a loss of €2,430 the first year to €9,010 after 11 years. In fact, among patients, there was no significant difference in salary during post-index follow-up (i.e., year 1 to year 11) ($P = 0.213$). The loss in salary among female patients compared with controls ranged from €1,900 in year 1 to €9,510 in year 11, and for male patients from €3,680 to €7,460 ($P < 0.005$ for all comparisons) (see Appendix Figs E1 and E2 in Supplemental Materials found at <http://dx.doi.org/10.1016/j.jval.2017.09.021>).

Results from the regression analysis of determinants of gross salary in patients with MS, comprising 2,957 individuals with at least one record of EDSS data during follow-up, are presented in Table 2. Evident from the table, we found that having a university education at diagnosis was associated with significantly higher income (for both sexes), as well as being married for men. In line with our expectations, we also found that the EDSS score, anxiety/depression, pain, and insomnia were associated with significantly lower income for women. For men, however, similar results were noted only for the EDSS score and anxiety/depression. Across follow-up, the mean EDSS score was 1.9 among women (SD 1.7; range 0–9) and 2.3 among men (SD 1.8; range 0–9). At index (i.e., first measurement during follow-up after diagnosis), 21% of patients had an EDSS score of less than 1, 28% between 1 and 2, 24% between 2 and 3, 15% between 3 and 4, 5% between 4 and 5, 2% between 5 and 6, 4% between 6 and 7, 1% between 7 and 8, and less than 1% had a score of more than 8.

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