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Social consequences of multiple sclerosis (1): early pension and temporary unemployment—a historical prospective cohort study

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Abstract

Multiple sclerosis affects young and middle-aged people and often leads to physical and cognitive handicaps. There is a need for detailed knowledge of the social consequences of the disease. We aim here to describe the course of the working life and career of multiple sclerosis patients at the time of onset and thereafter, in terms of probability of early pension and income development.

All 2538 patients with multiple sclerosis in Denmark with disease onset between 1980 and 1989, identified through the Danish MS-Registry, were included in this study. Twenty matched control persons per patient were randomly drawn from the civil registration system. Information on economic status was retrieved from Statistics Denmark. A survival analysis technique was used with onset as the starting point. We found that the probability of remaining without early pension was at 5 years 70% for patients and 97% for controls, and at 20 years 22% for patients and 86% for controls. Due to lower rates for early pension, gross income with time was lower in patients than controls. We conclude that multiple sclerosis seriously affects the economic life of multiple sclerosis patients, even within a few years of onset.

Keywords

cohort study, disability pension, early pension, early retirement, income, multiple sclerosis, occupational status, unemployment

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Introduction

Multiple sclerosis (MS), a disease mainly affecting young adults and middle-aged persons in their most active and productive years, often causes early occupational disability. However, few studies have estimated the magnitude of this effect, and they have led to contradicting results.

Hammond et al., in a cross-sectional study of 2307 patients with MS,[1] reported that 45% of men and 30% of women were on pension or had retired, but neither specified whether it was early pension or age pension nor provided information on mean age or disease duration. In contrast, in a cross-sectional study of 117 patients with MS, Stenager et al. found a markedly higher proportion of 70% receiving disablement pension, without gender specification.[2] In a recently completed questionnaire-based study, Kobelt et al. examined the social status of 13,186 patients with MS in nine European countries, showing that between 33% and 45% of them received an early pension.[3]

No published studies have addressed the specific question of temporary unemployment in patients with MS who are still able to work. Most of the previous studies have dealt with the proportion of patients with MS who were economically inactive, without distinguishing between patients being temporarily unemployed or having permanently retired. In a large cross-sectional Australian study,[1] 50% of male and 73% of female patients were found to be economically inactive, but no information on mean age or disease duration was given for the cohort examined. In the cross-sectional study of Kobelt et al.,[3] conducted in

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nine European countries on 13,186 patients with MS with mean age of 49 and mean disease duration of 18 years, the authors found that between 60% and 75% of them were unemployed. Concerning the income of patients with MS, literature is sparse. In a cross-sectional study conducted on 916 British patients with MS, Green et al. found a generally lower level of income in the MS households.[4] Comparing these studies is difficult because of the differences in populations, legislation and follow-up time.

To elucidate the occupational situation of patients with MS, and in particular to gain knowledge of the expected time to early pension, we have conducted a population-based prospective study with long follow-up. The primary focus of this study is to describe the course of the working life of patients with MS at onset and the time thereafter in terms of time to early pension, temporary unemployment and income, to be compared with matched controls from the background population.

Patients and methods

All patients with definite or probable MS, identified through the nationwide Danish MS Registry[5] with onset from 1980 to 1989, were included in the study. The patients and the control persons were followed from 1 January in the year after the year of onset of the index patient until 1 January of the year in which he or she met the endpoint in question, had emigrated, had died, or until 1 January 2004, whichever came first.

For each patient with MS, 20 control persons were matched to the index person by sex and year of birth and being alive at 1 January at the year of onset of the corresponding patient. They were drawn by random from the Civil Registration System. Subjects entering the MS Registry as patients with MS at a later point in time were not eligible as control persons.

Information on employment status, income, type of work and early pension was retrieved for each year throughout the observation period from the governmental institution 'Statistics Denmark' and the underlying Prevention Registry[6] for each individual subject. The employment status of a person was defined every year on 1 November and early pension was defined on 1 January. According to Statistics Denmark, 'unemployed' is defined as having been without paid work by 1 November of the corresponding year in economically active persons. Early pension is granted to subjects not being able to work either full-time or part-time, or undertake domestic work in the case of housewives.

A total of 2538 patients with definite or probable MS and 50,760 control persons were included in the study. The study was designed as a historical cohort study of patients with MS. We used a survival analysis technique and Cox regression for the analyses, which were performed with the statistical package SPSS version 17. We adjusted gross income to the general price index of 2008 to correct for inflation, and converted the currency from Danish Krone to Euros.

In our data sources from Statistics Denmark, information on a person's type of education was classified into 1320 different categories. We used these data as proxy parameters for the type of work and we scrutinized the list and dichotomized the categories into education leading to physical or non-physical work. Physical work was defined as any kind of work depending on manual or physical activity, whether it was highly skilled (e.g. surgeons) or unskilled (e.g. general labourers). Non-physical work included all other kinds of work, whether or not it requires particular intellectual capacity. The type of work was determined based on the level of education at the year of onset for the patients and at the same calendar year for the corresponding control persons. This was the only data source available for classification of work, and it has some limitations: persons may be misclassified if they change type of work from physical to non-physical, e.g. persons educated as skilled workers, but later working in administrative businesses.

Results

Study population

Of the 2538 patients with MS, 943 (37%) were men and 1595 (63%) women, giving a female : male ratio of 1.7 : 1. Mean age at onset was 35.3 years (95% confidence interval (CI) 34.9; 35.7) with virtually no gender difference, and the mean time from onset to diagnosis was 4.2 years (95% CI 4.0; 4.3).

Early pension

At time of onset 0.83% of the patients received early pension compared with 0.69% of the matched control persons ($p = 0.145$). For those not receiving early pension at entry, the probability of remaining without early pension, calculated by survival analysis technique, was at 5 years 70% for patients and 97% for controls; at 10 years 45% for patients and 93% for controls; at 15 years 31% for patients and 89% for controls; and at 20 years 22% for patients and 86% for controls (see Figure 1). The median time to early pension was 10 years for patients and 24 years for controls.

A sub-analysis of the two work categories, performed by Cox regression analysis (see Figure 2 left and right panel), showed that the likelihood of early pension for patients with physical work was 1.26 (95% CI: 1.14; 1.40) times that of patients with non-physical work. For control persons, this was nearly double, with the likelihood for subjects in the physical work category being 2.36 (95% CI: 2.20; 2.52) times that of persons in the non-physical work category.

The sub-analysis of men and women (data not shown) by both Cox regression and survival analysis technique showed for women a slightly higher probability of early pension in both groups, with only the control group reaching statistical significance. Comparison of the 1980–1984 onset cohort with the 1985–1989 onset cohort showed virtually no differences in time from onset to early pension (data not shown), and thus revealed no cohort effect within this time range.

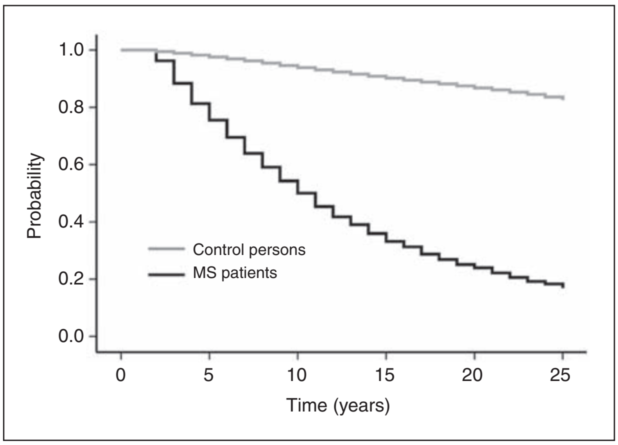

Figure 1. Probability of remaining in active employment after onset of multiple sclerosis. Key: grey, controls; black, patients.

Temporary unemployment

To examine the degree of temporary unemployment in patients with MS, a cross-sectional subgroup analysis was carried out, selecting persons currently available for the job market. Subjects older than 65 (age for Danish retirement pension) and those receiving early pension were removed from the analyses.

The frequency of temporary unemployment for economically active persons at 5, 10 and 15 years after entry was virtually the same for patients and control persons, with nearly no difference between men and women. For both patients and controls, persons with a physical work profile were more frequently temporary unemployed than those with a non-physical work profile (see Table 1).

Income

When comparing all patients with their control persons, we found a distinct difference in income trend for the two groups (Figure 3). After starting at an almost equal level, with patients' income only slightly lower, the mean gross income (adjusted to the 2008 price index) for the control

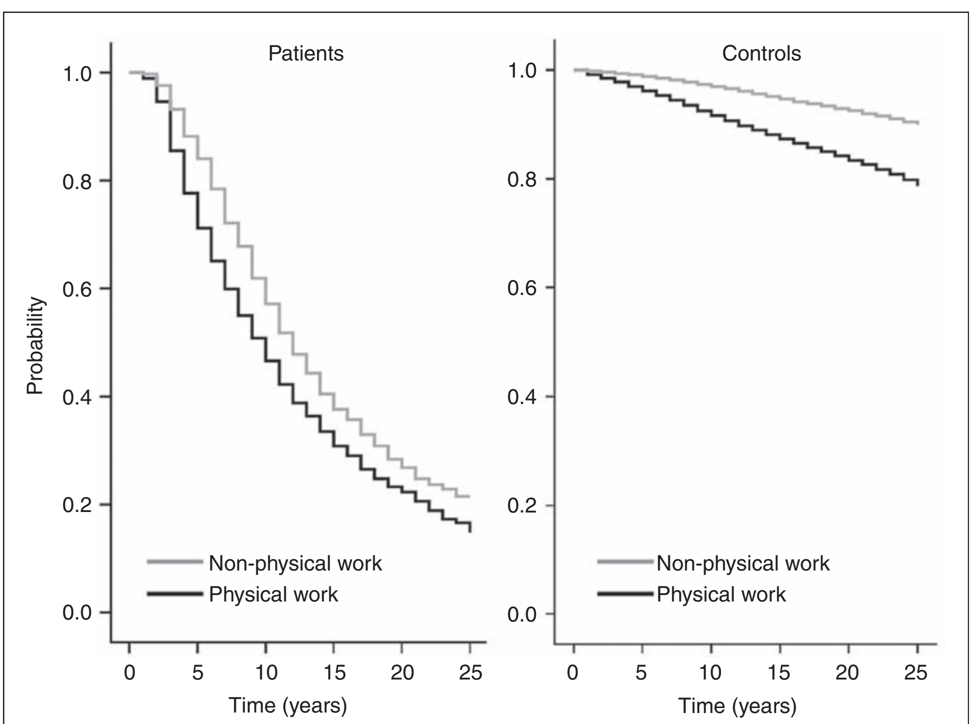

Figure 2. Left and right panel: probability of remaining without early pension after onset of MS for type of work in patients and control persons. Type of work: black, physical; grey, non-physical.

Table 1. Percent temporary unemployed by type of work and time in patients and controls

Years after onset			0	5	10	15
Patients	Work category	Physical	8.1	7.7	5.9	2.4
Proportion unemployed (%)		Non-physical	4.5	5.3	2.9	2.9
		All	7.3	7.2	6.2	3.9
Controls	Work category	Physical	8.6	8.6	7.1	4.5
Proportion unemployed (%)		Non-physical	4.6	4.4	4.2	2.8
		All	7.0	6.8	4.9	2.7

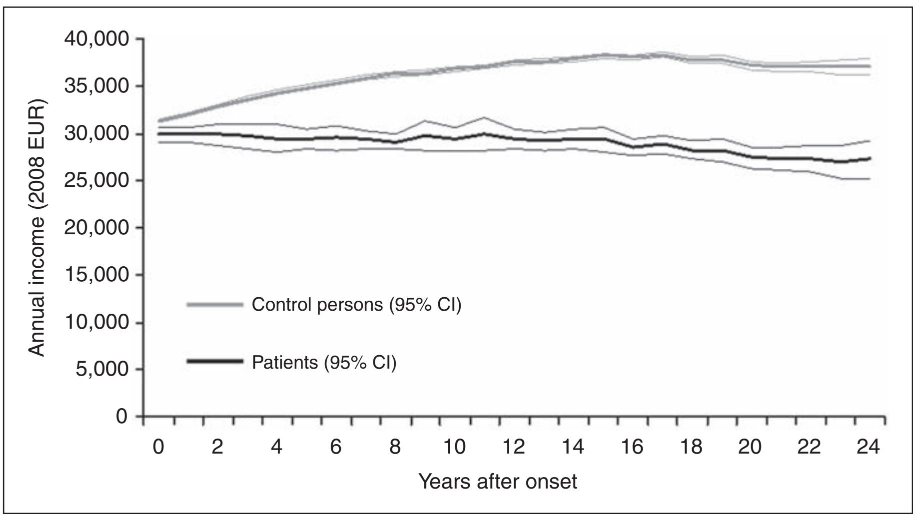

Figure 3. Development of annual mean gross income, early retirement pension inclusive. Key: light grey, controls; dark grey, patients.

group showed a constant and stable growth over the years, while the patients' income, after remaining stable for about 10 years, began to decline. After 20 years of follow-up the mean gross income for patients was only 70% of that of the controls. As a major reason for lower income among patients would be the lower rates of early pension, we analysed year-by-year income in the subgroups of MS patients and their control persons who were still economically active. The trends for income development when excluding early pension were almost similar in appearance (Figure 4). Again, the patients' mean income at the onset of MS was a little lower than control persons at the same time. However, income was constantly increasing for both groups, and after 10 years, the patients' income appeared to catch up that of control persons and subsequently remained at the same level.

Discussion

Early pension

Our findings are in line with former studies[1–3] confirming the fact that patients with MS, with time, leave the labour market and seek early pension. In contrast to previous research, in which risk of retirement has been derived from cross-sectional proportions at different times after onset, we performed analyses using a life-table methodology with onset as starting point and time to early pension as endpoint, enabling estimation of the time-dependent risk. Like other studies, we have shown that MS carries a high risk of early pension, within even few years after onset. With regard to a possible association between kind of work and risk of becoming an invalidity pensioner, the amount of previous research is sparse. Some studies have focussed on the correlation between level of education and risk of temporary unemployment, but one cross-sectional Swedish study by Sundström et al.[7] looked at full sick leave, finding that a lower educational level increased the risk of full sick leave fivefold compared with background population.

We found patients in the physical work category to be at only a slightly higher risk of early pension compared with patients in the non-physical work category (Hazard ratio 1.26), while the difference for control persons was close to twice of that

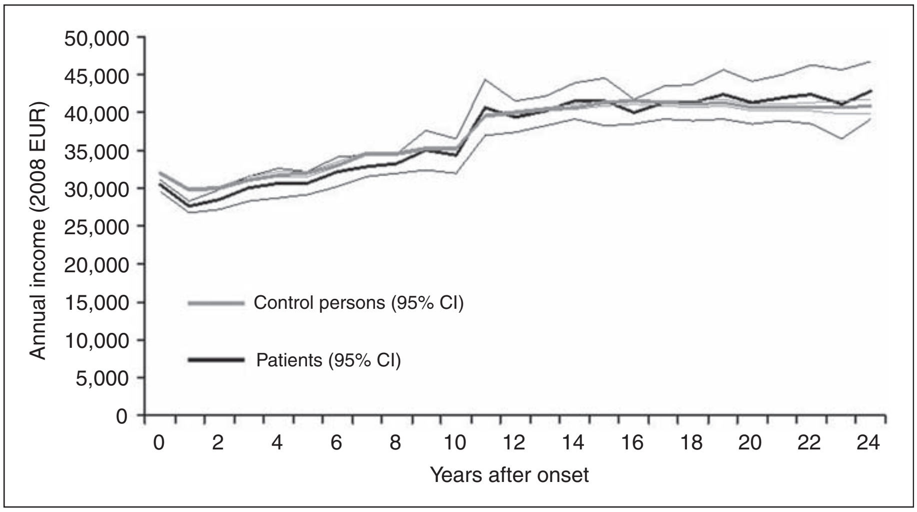

Figure 4. Development of annual mean gross income ignoring early retirement pension. Key: light grey, controls; dark grey, patients.

(Hazard ratio 2.36). Our methods are not completely comparable. Length of education, as used in the Swedish study, is only a proxy parameter of the type of work, used in our study. Although one could equal low educational level with physical work and full sick leave with early pension, our results are yet not completely comparable with other existing research.[1–3,7] In our classification of work a surgeon, for example, is classified as being dependent of physical (manual) activity although he or she certainly belongs to the higher educational class according to the classification used by Sundström et al.[7]

Patients with the non-physical work profile are at nearly same risk of early pension as patients with the physical work profile, probably reflecting the known cognitive impairment in patients with MS, which prevents them from carrying out intellectually demanding jobs with the same probability as physical impairment prevents patients from doing their physically characterized work. In contrast to Hammond et al.,[1] Catanzaro and Weinart,[8] and Mitchell,[9] who found that female patients with MS less often received disability compensation than male patients, our results showed no difference between men and women. A possible explanation could be provided by the a priori higher proportion of women being economically active in Denmark compared with other European countries and the Anglo-American populations. In countries where women are more often housewives, there would certainly be fewer women 'at risk' for receiving early pension. In Denmark, domestic activity is regarded as a trade, although not associated with income. This means that housewives, unable to perform their tasks because of chronic illness, are granted disablement pension.

Temporary unemployment

Previous research has shown that patients with MS are more often temporarily unemployed at various times after onset than are people from the background population.[1,3,4,9–16]

Our results are different: the proportion of temporarily unemployed among economically active patients does not exceed 9%, at neither 5 years nor at 10 years after disease onset, and is virtually the same for control persons. Moreover, there is a tendency for further decline 15 years after onset, with a proportion of temporarily unemployed definitely less than 5%. Possible explanations for this discrepancy would be that, in our calculations, we only included in the denominator persons not yet receiving early pension, while previous studies have calculated the proportion of patients not working irrespective of reason (temporarily unemployed or having retired permanently) among all patients. Another explanation could be related to the fact that 'the unemployed' always represent a selected group with an overrepresentation of season-dependent and more 'physical' jobs, as for example people in the building trade. Patients with MS, economically active after, for example, 10 years, tend to be employed in non-physical jobs, and hence have a smaller risk of unemployment. Another reason for the falling figures for temporarily unemployed could be the fact that in Denmark the unemployment rate has been tending downwards since the year 1990.

Income

In spite of a lack of sufficient data in the literature, there is general agreement on the negative impact of

MS on patients' income and income development. Our data provide the possibility to analyse the whole patient group as well as the subgroup of economically active patients. For the latter we have shown income development on the same level and comparable with the background population, indicating that as long as people are still in work, patients with MS have almost the same income as the matched background population. The MS patients' slightly lower income level at onset time could possibly be explained by temporary sick leave. As we had no information on sick leave in our data, we could not verify this assumption.

Strengths and limitations

Our study relies on a whole country's population data, retrieved from independent sources, and hence provides a robust validity and statistical strength. Our data on employment status, retirement and income for every subject and for every year over the study time span of 15 to 25 years provide a detailed picture of our cohort's economic status and development. Moreover, our data could be utilized to calculate certain aspects of costs of MS in the Danish population. The reason for choosing an onset cohort from as far back as the 1980s was to ensure a sufficient long follow-up. This choice has been made at the expense of topicality, as changes through the recent decades may have influenced the interaction between MS and the surrounding society.

When comparing our data with studies from different countries, we may bear in mind that differences in legislation could hinder a direct comparison of results. An analysis of annual allocation of early retirement pension (data not shown) demonstrates a constant rate for both patients and control persons over the observation period, indicating that there are no relevant effects of any change in social legislation for the period of interest.

Conclusions

Not unexpectedly, the risk of early pension is higher in patients with MS than in control persons. However, the difference is distinct even 5 years after onset, and the gap continues to widen, so 20 years after onset the probability of staying in employment is only 20%. In contrast to previous research the proportion of unemployed is virtually the same for patients and control persons.

For the subgroup of economically active patients, their income development and level is comparable to the background population. Differences between our study and studies from other countries do not reflect differences in the course of the illness, but rather differences in legislation and social structure.

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