Journal of the Neurological Sciences 367 (2016) 319–325

Contents lists available at ScienceDirect

Journal of the Neurological Sciences

journal homepage: www.elsevier.com/locate/jns

Longitudinal changes in sickness absence and disability pension, and associations between disability pension and disease-specific and contextual factors and functioning, in people with multiple sclerosis

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ARTICLE INFO

Article history:
Received 21 February 2016
Received in revised form 10 May 2016
Accepted 30 May 2016
Available online 12 June 2016

Keywords:
Multiple sclerosis
Sick-leave
Disability pension
Sociodemographics
Longitudinal studies
Risk factors

ABSTRACT

Background: Even though it is well known that disability due to MS is highly associated with employment status, the long-term longitudinal perspective on sickness absence and disability pension over the MS trajectory is lacking. In addition, further knowledge of risk factors for future disability pension is needed.
Objectives: To explore long-term longitudinal changes in the prevalence of sickness absence and disability pension in people with MS (PwMS), as well as to explore associations between disease-specific factors, contextual factors and functioning, and the outcome of future full-time disability pension.
Methods: A prospective, population-based survival cohort study, with a nine year follow-up, including 114 PwMS was conducted by combining face-to-face collected data and register-based data.
Results: The prevalence of full-time disability pension increased from 20% to 50%, however 24% of the PwMS had no disability pension at all at end of follow-up. Sex, age, disease severity and impaired manual dexterity were associated with future full-time disability pension.
Conclusions: The large increase in prevalence of PwMS on full-time disability pension during the MS trajectory, calls for the development and implementation of evidence-based interventions, aiming at keeping PwMS in the work force. Modifiable factors, such as manual dexterity should be targeted in such interventions.

1. Introduction

Multiple sclerosis (MS) is the leading cause of neurological disability in younger adults [1] and most people with MS (PwMS) face progressive disability in several areas over many years [2]. In addition, neurological disability due to MS is highly associated with employment status [3]. Even though most people with MS (PwMS) are in paid work or full-time education at diagnosis, many of them face a reduction in these activities only a few years thereafter [4,5]. There is a fair amount of studies exploring employment status in relation to MS but the literature regarding work disability, a concept including both sickness absence (SA) and disability pension (DP) [6], is very scarce [7]. Furthermore, the long-term longitudinal perspective including changes in work disability patterns over the MS trajectory is lacking, and national differences in sick-leave regulations and work place legislations challenge the ability to generalize results between countries. In the US, one study reported the prevalence of DP among PwMS to be 42% [8]. European studies have reported a prevalence of DP varying between 33% and 45% [9]. In Sweden, one study reported a three months prevalence of full-time DP of 31% [10]. Another Swedish study reported a 12 months prevalence of part- or full-time DP of 62% [7]. A limitation of some of these studies is that they are based on very different cohorts of PwMS [9], e.g. regarding ages, and/or self-reported data on work disability [9,10] which may cause selection bias and/or recall bias in the results. Furthermore, a long-term longitudinal perspective is lacking. By using a population-based sample and register-based data on work disability collected over the MS trajectory, valuable knowledge, applicable to large populations of PwMS, could be provided.

The impact of MS on the capacity to work, involves a complex interaction between different factors [11] and better knowledge of the associations between these factors can provide basis for effective interventions aiming at enabling PwMS to maintain working. Factors

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http://dx.doi.org/10.1016/j.jns.2016.05.055
0022-510X/

associated with work disability among PwMS include disease-specific factors: higher disease severity [3,5,12,13], progressive MS [5,13], longer disease duration [12,13]; contextual factors: higher age [3,5,14], lower level of education [3,12,14], lower socioeconomic status, negative attitudes of co-workers and employers, workplace discrimination, and disability benefits [15]; functioning: cognitive impairment [13,16], impaired manual dexterity [13] and fatigue [13,16]. In contrast, the use of immunomodulatory treatment might positively impact work capacity [17]. A limitation of some of these studies is the use of employment status as outcome measure instead of SA and DP [12–14]; employment status can include also other reasons for not being in work such as parental leave, being a homemaker, a student or being old-age retired. Additionally, in some studies, the studied risk factors are self-reported instead of collected face-to-face which may cause recall bias in the results [12,13].

In order to develop strategies and interventions, aiming to enable PwMS to retain in work, which can be generalized to large MS populations, there is a need for long-term longitudinal and population-based studies using register-based and face-to-face collected data. The aim of this study was therefore to, in a population-based sample of PwMS in Sweden, explore long-term longitudinal changes in the prevalence of SA and DP in PwMS as well as to explore associations between disease-specific factors, contextual factors and functioning, and the outcome of full-time DP, using register-based and face-to-face collected data.

2. Material and methods

2.1. Participants

A prospective population-based survival cohort study with a nine year follow-up of PwMS in Stockholm, Sweden was conducted. In order to obtain the utmost possible population-based ascertainment, all patients with MS from all hospital and private neurology clinics in Stockholm were identified and included in a study specific temporary data pool, including 2129 PwMS (inclusion period lasted from September 1999 to September 2002) [18,19]. A random sample representing 15% ($n = 321$) of the data pool was drawn. Inclusion criteria were a definite and informed MS diagnosis, age over 18 years, residency in Stockholm County, and no diagnosis of other severe neurological or psychiatric disease. In total, 196 of the 321 PwMS fulfilled the criteria and of them 166 (85%) PwMS gave informed consent to participate in the baseline study. For the purpose of data collection for the 9-year follow-up, the same PwMS were identified and those still alive were contacted through a postal letter and were, after written informed consent, included.

Since 65 years of age is the common age for old-age retirement in Sweden, only those PwMS below 65 years of age at baseline were included in the present study.

2.2. Data

Data collection regarding disease-specific factors (time since diagnosis, disease severity, disease course), contextual factors (age, sex, sense of coherence (SOC), use of immunomodulatory treatment, level of education, type of work), and functioning (mood, cognitive function, manual dexterity), was performed at baseline using face-to-face interviews during home visits and by collecting data extracted through medical records. The interviews included a comprehensive protocol with structured questionnaires and tests. Each home-visit was conducted by one of three physiotherapists or by an occupational therapist, all with clinical experience with neurologic assessment and calibrated for the purpose of the data collection. The data collectors assessed disease severity by using the Expanded Disability Status Scale (EDSS) [20]; and information on disease course. The assessment of disease severity and course was verified by a senior neurologist. Data regarding time since diagnosis (years) was collected from medical records as were data on immunomodulatory treatment, while data on level of education and work type were collected by interview. To assess SOC, the 13-item version of the Sense of Coherence Scale was used [21,22]. Mood was assessed using the Beck Depression Inventory II (BDI) [23,24]. In order to assess aspects of cognitive function, the Symbol Digit Modalities Test (SDMT) [25] was used. To assess manual dexterity, the Nine Hole Peg Test was used [26,27]. The categorization of the variables was performed according to recommended cut-offs (Table 1).

If unable to work due to disease or injury, in Sweden, all residents aged 16 to 65 years who have income from work or unemployment benefits are entitled to sickness benefits from the Social Insurance Agency (SIA). Among employed individuals, sick pay is in most cases paid by the employer during the first 14 days of a sick-leave spell. Disability pension can be granted to people aged 19 to 64 who, due to disease or injury, have permanently reduced work capacity, even if not having previous income from work. SA and DP can be granted for 25%, 50%, 75% or 100% of ordinary working time. Data regarding SA and DP from 1994 to 2012 (i.e. from four years before baseline through the 9-year follow-up) was obtained from the Social Security Agency. Those PwMS who had had sickness benefits from the SIA were defined as sick absent. All register-based data was obtained at an individual level using the unique personal-number linkage.

2.3. Statistics

Descriptive statistics were used to present contextual- and disease-specific factors, functioning, and changes in prevalence regarding SA and DP and mean annual work disability days. In order to calculate the mean annual work disability days, the part-time work disability

Table 1
Variables used in the crude and adjusted Cox regression analyses and instruments used for data collection, and categorization of the variables in the cohort of 114 people with MS.

Variables and instruments	Categorization
Age	≥51/<51[a]
Sex	Male/female
Sense of coherence:	
Sense of Coherence Scale (20)	Weak: 13–54 points/moderate/strong: 55–91 points (21)
Immunomodulatory treatment	Yes/no
Level of education	Compulsory school (≤9 years)/high school to university (≥10 years)
Type of work	Blue collar/white collar
Disease severity:	
Expanded Disability Status Scale (19)	Mild: 0–3.5/moderate: 4.0–5.5/high: 6.0–9.5
MS course	Progressive MS[b]/relapsing–remitting MS
Time since MS diagnosis	>10 years/≤10 years
Mood:	
Beck Depression Inventory II (22)	Depressive symptoms: ≥13/no depressive symptoms: <13 *(23)*
Cognitive function:	
Symbol Digit Modalities Test[c](24)	Age-related norms, written or oral reply. Impairment: ≥−1.5 SD from the mean/no impairment: <−1.5 SD from the mean (24)
Manual dexterity:	
Nine Hole Peg Tes (26) (26)t[d] (25)	Impairment: <0.5 pegs/s/No impairment: ≥0.5 pegs/s (26)

[a] The same categorization of age was used as in a previous study using the same baseline cohort [2].
[b] Progressive MS includes those with either primary progressive MS or secondary progressive MS.
[c] The test was primarily conducted with written response, for those people with MS unable to write the test was administrated orally.
[d] For the right hand.