

# 2014 Joint ACTRIMS-ECTRIMS Meeting (MSBoston 2014) MS Journal Online

## Poster Session I

### Caregivers, employment, and healthcare utilization

#### P001

#### Caregiver's burden in multiple sclerosis is higher in Mexican population

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**Background:** According to previous studies, 25% of caregivers of chronically ill patients have been reported to suffer some degree of burden. Latin caregivers experience caregiving as less challenging than Caucasians. Factors influencing burden include scholarship of the caregiver, relationship with the patient, motor and cognitive decline of the disease. To date there are no studies addressing the issue in Mexican caregivers of multiple sclerosis patients.

**Objectives:** To describe the prevalence and predicting factors of caregiver burden in multiple sclerosis within a Mexican population.

**Methods:** 99 Caregiver-patient pairs were recruited during scheduled office visits. Demographic data was recollected. Zarit Burden Interview (ZBI) was administered to caregivers and Expanded Disability Status Scale (EDSS) was calculated in each patient.

**Results:** Some degree of caregiver burden was found in 60.6%, being moderate or severe in 31.1%. The "Impact of caregiving" sub-dimension accounted for most weight of the construct. The median patient disability according to the EDSS was 5.5. Variables predicting caregiver burden were EDSS ( $p < 0.001$ , CI 95% 0.09-0.21), daily hours of caregiving ( $p < 0.001$ , CI 95% 0.81-0.91) and incomplete high-school for caregivers ( $p = 0.030$ , CI 95% 0.01-0.79). Daily hours of caregiving also predicted each subdimension of the ZBI independently. Kolmogorov-Smirnov test was used to determine the goodness of fit of the normal distribution of the interval variables. A likelihood ratio test was performed comparing the complete model with a reduced one including only the predicting factors, obtaining a significant  $p = 0.0014$  for 6 degrees of freedom.

**Conclusions:** Caregiver's burden prevalence was much higher than reported previously. In fact, even moderate or severe burden were higher than the overall burden described in other studies. Predicting factors were similar to those found in previous reports. Considering the higher prevalence of caregiver burden found, it is possible that the study sample was underestimated. If this is so, there's a chance that two more variables (Age of caregiver and Months spent as caregiver) could have reached significance providing the sample was enlarged. According to the results, neurologists should implement supporting measures for caregivers, addressing the time they spend with their patients.

Underlining of author represents the presenting author in each abstract

Future research should focus in other patient's variables and cultural environment.

#### P002

#### How do MS patients' sickness absence and disability pension trajectories develop over time? A nationwide cohort study of 3 543 MS patients

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**Background:** Multiple sclerosis (MS) generally occurs during the most productive period of life, and sickness absence (SA) and disability pension (DP) is common.

#### Objectives:

- 1) Characterize MS patients' SA/DP trajectory from five years before to five years after diagnosis and compare this with matched controls,
- 2) Explore if the progression of MS patients' SA/DP trajectories are associated with socio-demographics.

**Methods:** This population-based cohort study contains 3 543 Swedish residents aged 24-57 that were diagnosed with MS in 2003-2006 and 17 715 matched controls. Individuals with MS were followed, with regard to annual net days of SA and DP, from 5 years before until 5 years after diagnosis (t-5 - t5). Matched controls were followed over an equivalent time period. Adjusted odds ratios (ORs) with 95% confidence intervals (CIs) were calculated with General Estimation Equations (GEE) using a negative binominal distribution. A piecewise GEE model was fitted to evaluate if socio-demographics influenced the progression of MS patients' SA/DP trajectories at three distinct time periods, i.e., t-5 - t-1, t1 - t1 and t1 - t5. Differences of SA/DP progression were assessed by examining the interactions between socio-demographics and time.

**Results:** MS patients mean SA/DP days increased gradually between t-5 to t-1 (46 to 77) followed by a sharp increase (t1, 136), after which only a marginal increase was observed (t5, 145). Matched controls had less SA/DP days at all studied years, although the difference increased over time from an adjusted OR of 2.01 (1.93-2.08) to an adjusted OR of 5.00 (4.82-5.18) at t5. Men with MS had a sharper increase in SA/DP days during the period before diagnosis, i.e. t-5 - t-1, adjusted OR 1.05 (1.01-1.09). A lower educational level was associated with a less marked SA/DP progression, OR 0.94 (0.88-0.99) around the time of diagnosis t1 - t1, while the reverse scenario was detected during the time period that followed, t1 - t5, OR 1.10 (1.04-1.16).

**Conclusions:** Individuals with MS have a markedly higher risk for SA/DP than matched controls even 5 years before diagnosis.

**P003****Knowledge and attitude towards multiple sclerosis in Turkey**

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**Background:** Multiple Sclerosis is an inflammatory, autoimmune and neurodegenerative disease which effects young adults. The patients have many social problems. In many countries especially in developing ones, there are little knowledge about the disease and its course in the community. So that the patients may be lack of social support during their lives.

**Objectives:** The aim of this study was to investigate the perception of Multiple Sclerosis in Turkey, in an eastern city Kütahya.

**Methods:** The Survey of multiple sclerosis patients, their relatives and control group on the Knowledge, Attitudes, and Behavior Regarding the Disorder was used and included questions on descriptive characteristics, familiarity with multiple sclerosis (MS), attitudes toward MS, and understanding of MS.

**Results:** 71 MS, 46 relatives of MS patient and 40 control group included in the study. The control group were consisted of the people which had no MS diagnose or no relatives or friends with MS. Mean age of the MS patients, relatives and control group were 37yr (min19-max56), 40yr(min19-max66), 39(18-67), respectively. In the MS patient and relative groups; 10(14%) and 4(8.7%) of them concealed the diagnosis from other people. Both the patient and relatives groups had knowledge about the symptoms of the disease; however in the control group 30 (75%) people had no idea about the disease or the symptoms or about the etiology. Of the patients 61(85.9%) had no social problems, while 5(7%) had been fired of their work and 3(4.2%) had stigmatization. But from the control group 15 (37.5%) people thought that MS patients were stigmatized or having social problems in the society.

The number of participants who would allow their child marrying someone with MS was significantly higher in MS patient group than control group ( $p < 0.05$ ). Of the patient and relatives groups 4(%5.6) and 6(%13) had decided to use alternative herbal medicine in addition to medical treatment, respectively.

In the control group 7(17.5%) of them thought not to employ a MS patient, while 27 (67%) of them thought to employ a MS patient for only easy works.

**Conclusions:** Although understanding of MS was favorable in MS patients and in relatives of MS patients, it wasn't well understood in the community. Educating the community about MS and personal contacts must be the major strategies against understanding MS patients and their social problems.

**P004****Early loss of working capability in a Swiss cohort of patients with multiple sclerosis**

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**Background:** Diagnosis and disability associated with multiple sclerosis (MS) have far reaching implications on the patient's private and professional life. Notably, MS patients experience some of the highest rates of unemployment among individuals with severe and chronic disabilities.

**Objectives:** To assess working capability and employment status in a cohort of Swiss patients with MS.

**Methods:** A cross-sectional study was conducted over a period of 12 months among patients treated at the outpatient clinic for MS at the Inselspital, a tertiary care hospital at the University of Bern, Switzerland. The paper-based questionnaire inquired about details of current employment and impact of MS-related disability on working capability. The survey was supplemented by clinical data derived from the most recent medical report.

**Results:** The questionnaire was handed out to 644 patients and returned by 449 (68%). Individuals above the retirement age ( $n=44$ ) were excluded. A total of 405 patients (women 266, 66%) with a mean age of 44 years (range 18-64), median EDSS of 3.0 (range 0-8.5) and median disease duration of 12.4 years (range 1-43) were subjected to further analysis. Full-time employment was declared by 108 patients (27%, median EDSS 2.0 (0-6.5), mean age 40.8 y (19-62), median disease duration 10.5 y (range 1-43) women 58 (54%). A total of 104 patients (26%, median EDSS 3.0 (1.0-7.0), mean age 45 y (26-63), mean disease duration 12.4 y (range 1.7-34.0) women 68 (65%)) had scaled down to part-time work because of disease-related issues. Complete inability to work was reported by 110 patients (27%, median EDSS 5.0 (1-8.5), mean age 48 y (25-65), median disease duration 16.0 y (range 3.2-43.0) women 73 (66%)). 83 patients (21%) were not employed but reported other reasons than MS (mostly care for children, household).

**Conclusions:** Our data further corroborate the toll this disorder takes on the life of the patients and caregivers early in the course and despite emerging treatment options. Only less than one-third of the patients in a cross-sectional cohort of Swiss MS patients with mostly mild impairment were fully employed. Part-time work is common despite limited disability. Further efforts need to be taken in order to develop measures to preserve and regain working capability. Moreover, studies aimed to assess potential gender- and education-related inequalities are warranted.

**P005****Profile of social participation of multiple sclerosis adults in Québec city**

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**Background:** Many studies have presented the physical and psychological consequences of chronic degenerative diseases such as multiple sclerosis (MS). Only a few studies have focused on the impact on social participation. Our observations suggest that social roles seem more affected than activities of daily living (ADLs).

**Objectives:**

- 1) Describe the social participation of people living with MS, and
- 2) determine what personal factors may influence it.

**Methods:** Participants were recruited via a local MS organization. Data were collected through telephone interviews using