

Employability situation in patients diagnosed with multiple sclerosis in Brazil

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Introduction: Multiple sclerosis (MS) is an inflammatory and demyelinating disease of the central nervous system that presents a chronic course with episodes of exacerbation. MS affects people at the peak of their productive life, between 20 and 40 years of age, and can cause permanent neurological disability, which can exert influence on their quality of life, income maintenance and employment relationship.

Objective: To evaluate the employment status of Brazilian patients with MS and its modification along the disease course.

Methodology: We performed a cross sectional study concerning occupational status, demographic and clinical data regarding the year of their first symptom and diagnosis. The study was approved by the University's Ethics Committee and carried through an electronic survey sent to the patients affiliated to a patient committed organization (Amigos Múltiplos pela Esclerose). The survey included 12 questions on demographic, social and occupational status at the moment of diagnosis and present day, and also information regarding the time length from the first symptom to diagnosis.

Results: Up to May 25th 431 patients had answered the survey. Mean age of onset and current age were 28.2 and 35.7; mean time to diagnosis and disease duration were 2.5 and 7.7 years. 51.7% live in the State of São Paulo, 49.6% were married, 41.1% single, 8.8% divorced and 0.5% widow. 68% had a university degree and 29% had finished high school. 96% of the patients had a professional occupation contributing to the family income at least once in their lives, 78% of them were employed at the time of diagnosis but only 58% of all patients are currently employed. The evaluation of employment status through disease's course disclosed that 52% kept and 26% lost their job, 15% were and remained unemployed and 7% were unemployed and became employed. When questioned if the disease MS had any influence in obtaining or keeping their employment status, 72% considered that the disease had a major influence against maintaining their occupational status.

Discussion and conclusion: This study discloses for the first-time the employment status of large sample of patients with MS from most Brazilian regions. The rates of unemployment nearly double during the disease course, and only 58% of persons with MS in their productive years are employed, a very low rate considering that nearly 2/3 of them hold an academic degree. The reasons for keeping or losing a job were not evaluated, as our first intention is to know the employment status in these patients. Nevertheless, these results raise an important concern regarding the use of pension funds and social benefits for a very young population that could be producing instead of using public resources. These are preliminary results, the survey will remain active up to July 30th, and we will later analyze the complete dataset and the influence of age of onset, schooling, time spent between first symptom and diagnosis confirmation and disease duration on employment status.

Keywords: Multiple sclerosis; Diagnosis; Brazil.