Access to social security benefits among multiple sclerosis patients in Italy: A cross-sectional study.

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ABSTRACT

Background: Knowledge concerning the predictors of social security benefits and the proportion of Multiple Sclerosis (MS) patients receiving these benefits is very limited.
Objective: To estimate the likelihood of receiving social security benefits for Italian MS patients.
Methods: From September 2014 to November 2015, we interviewed MS outpatients from two Italian MS clinics to collect information regarding their personal data, clinical and working history, and access to social security benefits. We performed both univariate and multivariable analyses to evaluate the predictors for receiving social security benefits.
Results: We interviewed 297 patients, with a mean age of 49.5 (± 10.7) years; 71.4% were females. About 73% of patients had a relapsing-remitting (RR) course and the median EDSS score was 2.5 (IQR 1.5–6). About 75% of MS patients received a full exemption from co-payments, while the proportions of people who enjoyed each of the other social security benefits were lower, ranging from 8.8% (car adaptation) to 32% (disable badge). At multivariable analysis, the probability of obtaining each of the benefits was significantly associated with the EDSS score: walking aids (OR 3.9), care allowance (OR 3.6), disabled badge (OR 2.4), exemption from co-payment (OR 1.6) and allowed off work permit (OR 1.7). Only the probability of obtaining an allowed off work permit was also influenced by comorbidities (OR 2.9) and a higher education (OR 2.2).
Conclusion: Except for full exemption from co-payments, the proportions of MS patients who enjoyed social security benefits seem to be limited in our study sample. The EDSS score is the strongest predictor of the probability of receiving all the benefits. Only a small proportion of patients received care allowance and working permits, probably because such benefits are only granted to people with a high level of disability. On the other hand, the low proportion of patients who enjoyed fiscal benefits for home and car adaptations could have been influenced by the way such benefits are granted in our country.

1. Introduction

Multiple sclerosis (MS) is a chronic neurologic disease whose progression limits MS patients in many relevant aspects of everyday life, adversely affects working, psychosocial and many other domains, globally worsening their quality of life (Lorefice et al., 2018).

The impairments in motor function and visual acuity limit MS patients' ability to independently walk, wash and shower, enter private and public buildings and use public transportation. Cognitive impairments limit their abilities in many aspects of life, leading to a range of severe to complete incapabilities, which require assistance in daily living. Therefore, many aids and services have been developed to help disabled patients overcome their physical impairments and maintain their independence as long as possible.

To reduce the impact of motor impairments, patients need to buy aids, such as crutches, walkers and manual or electric wheelchairs. Additionally, driving ability is frequently reduced by motor or visual impairments in MS patients. Different instruments exist to facilitate disabled patients' ability to get in and out of cars and drive, such as a double rear-view mirror, steering wheel controls, or automatic drive.

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Disabled patients frequently need to adapt their homes to abolish architectural barriers, such as installing ramps or lifts to facilitate access to different floors or adapted toilets, bathtubs or shower stalls to facilitate access to bathrooms. Finally, patients with severe cognitive or physical disabilities need informal or professional care at home or must reside in rehabilitation or nursing homes.

Many of such aids and services are costly and may not be accessible to MS patients out of pocket. A study conducted in Italy in 2015, showed that MS patients sustained relevant costs for aids, community services (nurse visits and home help) and investments, especially those with severe disability (EDSS score ≥ 7) who spent €1.600,00 for investments and €5.648,00 for community services on average. Nonetheless, the main cost was represented by informal care given by family members which raised a mean annual cost of € 5.105,00 for MS patients with moderate disability (EDSS 4–6.5) and €12.328,00 for MS patients with severe disability (Battaglia et al., 2017). Therefore, many health systems, public agencies, charities and private institutions grant aids and services for free to disabled patients or provide financial contributions to help them purchase the services they need.

Even if aids and services for disabled individuals are costly and relevant to MS patients, few studies have described access to these welfare benefits, particularly those associated with driving (Marcotte et al., 2008; Schultheis et al., 2009; Schultheis et al., 2010a; Schultheis et al., 2010b).

Therefore, we conducted this study in Italy to: 1) estimate the proportions of MS patients who enjoyed social security benefits for disabled individuals, such as walking aids and exemptions from co-payments; public financial help for car adaptations and disabled badges; financial assistance for home adaptations; care allowances; and allowed off of work for medical reasons; 2) evaluate which factors may influence the possibility of obtaining such benefits by public institutions.

This paper describes part of the results of a wider study aimed to analyse the characteristics of MS patients who benefited from social protections.

2. Materials and methods

2.1. Italian regulations on social security benefits in the disabled

According to Italian laws, disabled patients may receive social security benefits to reduce the impact of their disability on everyday life. Medical commissions evaluate the right to receive such benefits according to the degree of disability and the independence in walking and activities of daily living.

Social security benefits are as follows:

– to support walking ability: free supply of walking aids, such as crutch/walker/wheelchair;
– to afford access to diagnostic and therapeutic services and drugs: exemption from co-payments;
– to maintain driving ability: VAT reduction (from 22% to 4%) if they buy a new adapted vehicle or make adaptations, a tax break (19%) on vehicle purchases, and disabled badges for the disabled;
– to overcome architectural barriers at home: financial contribution by the municipality (partial reimbursement) where they live to install devices (e.g., ramps, rail or elevators) or a tax break (36%) on the expenses required to install them;
– to have continuous assistance: care allowance of € 509,00 per month if the patients need continuous assistance in activities of daily living or continuous help by another person to walk;
– to reconcile work with assistance needs: allowing time off work for medical reasons (two hours a day or three days per month).

2.2. Questionnaire validation and interviews

We designed a 90-item questionnaire to collect data regarding 1) personal data (gender, age, education level, marital status, driving) - 11-items; 2) clinical history (time from onset, time from diagnosis, course of disease, EDSS score, comorbidities and being in a wheelchair) - 13-items; 3) working history (current and previous employment) - 11-items; 4) access to contributory and non-contributory disability pensions (DP) - 30-items; and 5) access to social security benefits (free supply of walking aids; exemption from co-payments, fiscal benefits and financial contribution to adapt or buy vehicles and overcome architectural barriers; disabled badges; care allowance) - 25-items.

We validated the questionnaire through personal interviews of 18 patients who were randomly selected at the Orbassano centre. The pilot study showed that many patients were unable to accurately reconstruct their clinical history and/or which benefits their received and when. Thus, patients were contacted in advance and asked to exhibit the documents about their social security benefits at the moment of the interview.

We calculated the sample size using a study power of 80%, a hypothetical population of 1,500 patients who yearly access the two clinics involved in our study and an expected prevalence of contributory DP of 20% ± 5% derived from the pilot study.

From September 2014 to November 2015, we randomly selected consecutive outpatients from two MS clinics in Northern and Central Italy (Orbassano and Siena). Every patient underwent a semi-structured interview conducted by two physicians specialized in insurance medicine. Clinical data were collected from the outpatient charts, in collaboration with the neurologists of the two MS clinics. Data on social security benefits were collected from official documents and certificates provided by the patients. Personal data and working history were obtained during the interview.

Regarding social security benefits, we collected data on walking aids (crutches/ walker/wheelchair/none); help with vehicles and home adaptations (granted/not granted and used/not used); care allowances and disabled badge (granted/not granted); exemption from co-payments (granted/not granted); and allowed off work for medical reasons (granted/not granted).

All participants were informed about the nature and the purpose of the study, received an informational leaflet, and were requested to provide a written consent to participate in the study.

2.3. Statistical analysis

Descriptive data are shown as absolute and relative (%) frequencies of the different modalities for categorical data and as the mean ± standard deviation (SD) or median and interquartile range (IQR) for continuous variables.

Univariate analyses were carried out using a *t*-test (or Wilcoxon rank-sum test for non-normal distributions) for continuous variables and chi-square test or Fisher exact test for qualitative variables to evaluate the association between having or not received each social security benefit and the demographic, clinical and working characteristics of the MS patients (i.e., gender, education level, MS course, EDSS score, comorbidity, working area). For the categorical variables, odds ratios (OR) and their confidence intervals (CI 95%) were also calculated.

To adjust for the relative effect of each factor associated with having received each social security benefit, multivariable analyses were performed with the variables that were found to be significantly associated with the probability of receiving each social security benefit in the univariate analyses, also adjusting for gender and age. Specifically, we designed a logistic regression model for each social security benefit. Because the EDSS score and the course of MS were found to be intercorrelated, the course of the disease was removed from the models, and the EDSS score was maintained as an indicator of the degree of