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 multivariate analyses to evaluate the risk factors for social security benefits.

Results: We interviewed 297 patients, 71.4% of whom were females with an overall mean age of 49.5 ± 10.7 years. About 72.8% of patients had a relapsing-remitting (RR) course and the median EDSS score was 2.5 (IQR 1.5-6). About 75,4% of MS patients received a full exemption from copayments, 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 multivariate analysis, the probability of obtaining each of the benefits was influenced by 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 by a higher education (OR 2.2).

Conclusion: Except for full exemption from co-payments, the proportions of MS patients who enjoyed social security benefits seems to be limited. The EDSS score is the stronger predictor of the probability of receiving each of the benefits. Reduced proportions of patients received disabled badges, care allowance and working permits probably because such benefits are only granted to people with a high level of disability. On the contrary, 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.

1. Introduction

Multiple sclerosis (MS) is a chronic neurologic disease, and its progression limits MS patients in many relevant aspects of everyday life, worsening their quality of life.

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 their 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 for 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.

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. 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 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 to1) 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 and 2) evaluate which factors may influence the possibility of obtaining such benefits by public institutions.

This paper describes a 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 copayments;
- 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; and
- to reconcile work with assistance needs: allowing time off work for medical reasons (two hours a day or three days a month).

2.2. Questionnaire validation and interviews

We designed a questionnaire to collect data regarding 1) personal data (gender, age, education level, marital status, driving); 2) clinical history (time from onset, time from diagnosis, course of disease, EDSS, comorbidities and being in a wheelchair); 3) working history (current and previous employment); 4) access to contributory and non-contributory disability pensions (DP); 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).

We validated the questionnaire through personal interviews of 18 patients who were randomly selected at the Orbassano centre.

Then, we calculated the study sample size using a study power of 80%, a hypothetical population of 1500 patients and a 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. Clinical data were collected from the outpatient charts. 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 copayments (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 \pm standard deviation (SD) or median and interquartile range (IQR) for continuous variables.

Univariate analyses were carried out using a t-test (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 having 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 evaluated. Because the EDSS score and the course of MS were found to be inter-correlated in each model, the course of the disease was removed from the models, and the EDSS score was maintained as an indicator of the degree of disability.

The final models are shown in tables 1 to 5. Receiving a social security benefit (walking aids, exemption from co-payment, help with vehicle and home adaptations, disabled badges, care allowance and allowed off work for medical reasons) was considered the dependent variable in each logistic regression model. Gender, age, time since the onset of the disease and the EDSS score were

included as independent variables to evaluate their adjusted effect on the probability of receiving walking aids, exemption from co-payment, help with home adaptations and care allowances. Age, time since the onset of the disease, the EDSS score and not driving were included as independent variables to evaluate their adjusted effect on the probability of receiving disabled badges and help with vehicle adaptations. Finally, age and comorbidity were included as independent variables to evaluate their adjusted effect on the probability of receiving time allowed off work for medical reasons.

All tests were two-tailed, and the statistical significance level was set at 0.05.

All the analyses were performed using Stata SE 13 (StataCorp. LLC, Texas, US).

3. Results

3.1. Personal characteristics and development of the disease.

We interviewed 297 patients, including 212 (71.4%) females and 85 (28.6%) males. Mean age was 49.5±10.7 years, without significant differences by gender. In total, 198 (66.7%) patients were from Orbassano, and 99 (33.3%) patients were from Siena. No significant differences were observed between the two centres, so that all analyses have been performed on the whole sample.

Among the interviewed patients, 230 (77.4%) were married or lived together with an unmarried partner, while 67 (22.6%) were single.

One hundred and twenty-three (41.8%) patients had a primary or lower secondary education, 116 (39.5%) had a high school education, while 55 (18.7%) had graduated. In total, 75 (25.3%) patients did not drive.

3.2. Clinical and working history

At the time of the interview, 214 (72.8%) patients had a relapsing-remitting (RR) course, 70 (23.8%) patients had a secondary-progressive (SP) course and 10 (3.4%) patients had a primary-progressive (PP) course.

The mean duration of the disease was 14 ± 6.2 years from diagnosis and 18.9 ± 7.8 from the onset of symptoms, and the median EDSS score was 2.5 (IQR 1.5-6). Both the mean duration of the disease from the onset of symptoms (17.5 ±4.7 in PP; 17.4 ±6.9 in RR; and 23.9 ±8.8 in SP) and the median EDSS (2, IQR 1-3.3 in RR; 6.5, IQR 6.5-7 in PP; and 6.5, IQR 6-7.5) varied significantly among patients affected by different MS courses (p<0.001). In total, 68 patients (22.9%) were using a wheelchair or walker and 169 (56.9%) patients had at least one comorbidity.

Approximately 60.6% of the patients (180 subjects) were employed as follows: 148 (82.2%) were employed in the private sector; 145 (75.5%) were employed in the tertiary sector; 145 (78.4%) were employed full time; and 38 (21.1%) were employed in a job requiring physical work (ISCO occupation class 6 to 8). Fifty-nine (19.6%) patients were retired. Sixty patients (20.2%) were unemployed, and the unemployment rate was 24.1%, which was higher in females than males.

3.3. Walking aids, exemption from co-payment and disabled badges.

One hundred fourteen (38.4%) patients were using a walking aid; of them, 47 used a crutch, 15 used a walker and 52 used a wheelchair. Seventy-six (25.6%) MS patients obtained these aids free of charge.

Some 224 (75.4%) patients obtained a full exemption from co-payments, which is granted to disabled individuals. Ninety-five patients (32.0%) obtained a disabled badge.

The probability of receiving each of these benefits was significantly associated with age and the characteristics of the disease (duration of the disease from onset, progressive course, and EDSS score) in the univariate analyses. In particular, having a progressive course was a strong predictor of receiving walking aids and a full exemption from co-payment because it increased the probability of receiving such benefits approximately 20 times (21.3 and 19.4 times, respectively). In the multivariate analysis, the probability of receiving walking aids, exemptions from co-payment and disabled badges significantly increased with the increase of the EDSS (Table 1 to 3).

3.4. Care allowance

Thirty-eight (12.8%) patients received a care allowance. The probability of receiving this benefit was significantly associated with age and some of the characteristics of the disease (progressive course, duration from onset and EDSS) in the univariate analysis. In the multivariate analysis, only having a higher EDSS score was found to be a significant predictor of receiving this benefit (Table 4).

3.5. Allowed time off work for medical reasons

Seventy-nine (26.6%) patients were allowed to enjoy time off work for medical reasons. Of them, 42 were employed and used this benefit to decrease their work time while for the remaining 37 patients, who were unemployed, the caregivers used the benefits provided.

Some of the characteristics of the disease (progressive course, EDSS score and having comorbidities) were significantly associated with the probability of receiving this benefit in the univariate analysis. In multivariate analysis, a higher education, having co-morbidities and an increasing EDSS score turned out to be significantly associated to the probability of receiving time allowed off work for medical reasons (Table 5).

3.6. Car and home adaptations.

In total, 35 (11.8%) patients adapted their vehicle; the proportion of patients who adapted their vehicles was the same (12%) among those who declared they continued to drive and those who quit driving. Their median EDSS was 6.7 (IQR 6-7.5). At the same time, 26 of the 35 patients (74.3%) were entitled to receive fiscal benefits to adapt their vehicles (VAT discounts and tax breaks), but only 20 (57.1%) declared to have benefitted from them.

Additionally, 43 patients (14.5%) declared they installed devices at their homes to overcome architectural barriers. Thirty-six of them (83.7%) were entitled to obtain taxes breaks or financial

contributions from the municipality, but only 20 (46,5%) declared to have benefitted from these financial benefits. Their median EDSS was 6.9 (IQR 6-7.5).

In the univariate analysis, the probability of using fiscal benefits both to adapt homes and vehicles was significantly associated with age and variables that define the progression of the disease (progressive course, duration from onset and EDSS score). However, the probability of using these benefits significantly increased only with the increase of the EDSS in the multivariate analysis.

4. Discussion

To the best of our knowledge, this is the first study attempting to estimate the number of MS patients who enjoy the multiple social security benefits aimed to reduce the impact of their disability and the factors that may influence the possibility of obtaining such benefits by public institutions.

Excluding those receiving a full exemption from co-payments, the proportion of people who enjoyed social security benefits is low in our sample and the EDSS score is the stronger predictor of the probability of receiving each of the benefits. These results may be explained by the characteristics of our sample, which was mainly represented by patients with RR-SM and a low level of disability (median EDSS =2.5).

In particular, a low median EDSS score may explain the limited proportion of patients who benefitted from the services provided by the health and social security system to people with a medium-high (walkers, wheelchairs, disabled badges) or high (care allowance) motor or global disability.

In our study, the proportion of people who adapted their home or vehicle was particularly low (14.5% and 11.8%, respectively). Indeed, even if these proportions are slightly higher than the ones reported by Kobelt (9.5% and 3.8%, respectively), our results showed that the proportion of patients who enjoyed fiscal and financial benefits to obtain such adaptations was very limited (6.7%) (Kobelt et al., 2006).

These data may be partly explained by the way such benefits are granted. According to Italian legislation, disabled individuals must always pay out of pocket to buy a new vehicle or adapt their vehicle or home. It is only afterward that they may enjoy a partial reimbursement of the expenses through tax reductions and breaks or financial contribution. Thus, lower income MS patients may have difficulties in paying out of pocket and, consequently, renounce to buy aids, adapt their car, adapt their bathroom, or place ramps or elevators at their homes. Indeed, previous studies showed that MS patients have significant reductions in their income and that the cost sustained to adapt a home can be very high (Kobelt et al., 2006).

Additionally, tax breaks may not reduce but rather increase inequalities because unemployed patients and lower income individuals may be exempted from taxes due to their reduced income. Thus, they cannot use tax breaks to recover part of the expenses they paid to adapt their home or vehicle.

In addition, further reasons may explain the low proportion of MS patients who adapt their vehicle. Schultheis and colleagues found that MS patients with self-reported visual difficulties had worsened colour perceptions than both MS patients without visual difficulties and healthy controls (Schultheis et al., 2010a). These data are relevant because colour perception significantly contributes to safe driving. Furthermore, in a recent experimental study, 17 MS patients and 14 healthy controls participated in a driving simulation. The MS patients had greater deviations in lane position, missed at least 1 of the divided attention targets, and had greater difficulty in tracking the movements of the lead car (Schultheis et al., 2010b). These studies had limited sample sizes and excluded MS patients affected by psychiatric diseases or who were taking drugs that can negatively influence their ability to drive, such as benzodiazepines, sedatives or analgesics. These factors may have underestimated the limitations to driving among MS patients. The results of the studies mentioned above highlight that MS patients may have disabilities that cannot be overcome by available vehicle adaptations and as such, they may opt to quit driving instead of adapting their vehicle to continue driving.

Previous studies have shown that MS patients and their caregivers voiced a strong need for qualified personnel and care coordination in home care and that MS patients who need assistance at home often receive informal care by their relatives (Roessler et al., 2013; Kobelt et al., 2006; McCrone et al., 2008; Borreani et al., 2014). To reduce the economic burden of informal care, in Italy, MS patients may receive a care allowance, and the relatives who care for the patients have the right to a 3 days per month paid working permit.

In our sample, the proportion of MS patients who received a care allowance and with relatives with paid working permits were 12.8% and 12.5%, respectively. Our results are in line with the ones found by McCrone (McCrone et al., 2008). Collecting from a mailed questionnaire from a sample of MS patients in Great Britain and Northern Ireland, McCrone showed that during the previous six months, only about 15% of MS patients received home help (McCrone et al., 2008). At the same time, our estimates are lower than the ones reported by Kobelt and colleagues who showed that 20.4% of MS patients required home help in Italy in 2005. Nonetheless, the higher median EDSS in Kobelt's study may explain this difference (Kobelt et al., 2006).

This study design has some limits. Recall bias may have negatively influenced our results as some of the patients may have not completely reported data regarding the aids and services they used and the contributions they received by the state. Furthermore, as other previous studies based on outpatient interview, our results may suffer from selection bias which may underestimate the proportion of MS patients who receive welfare benefits. Indeed, patients with a longer history of illness and a more severe and chronic disability are likely to be excluded from the study because they do not usually undergo periodical examinations. Finally, this study did not analyse the economic status of MS patients which may influence access to some of the social security benefits.

5. Conclusion

The EDSS score is the stronger predictor of the probability of receiving social security benefits in our study. Even if most of MS patients received a full exemption from co-payments, the proportions

of MS patients who enjoyed other social security benefits were limited. Disabled badges, care allowance and working permits are only granted to people with a high level of disability. Thus, our results may be partly explained by low medium EDSS of the sample. On the contrary, the low proportion of patients who enjoyed fiscal benefits for home and car adaptations seems to be influenced by the way such benefits are granted. Further studies are needed to investigate whether MS patients with higher levels of disability can reach social security benefits and to better describe MS patients needs for home adaptations and driving.

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Table 1. Predictors for receiving walking aids.

walking aids (n=76)	Receiving	not receiving	not receiving univariate analysis		multivariate analysis	lysis
	(%) u	(%) u	OR (95% IC)	p-value	OR (95% IC)	p-value
gender (M)	20(26.3%)	65 (24,9%)	0.9 (0.5-1.5)	0.607	0.55 (0.20-1.50) 0.244	0.244
age (mean±SD)	54.8±9,9	47.7±10.4	1	<0.001	<0.001 1.00 (0.96-1.05) 0.965	0.965
progressive course	55 (73.3%)	25 (11,4%)	21.3 (9.3-49.0)	<0.001	ı	ı
EDSS (median; IQR)	6.5 (6.0-7.5)	2.0 (1.0-3.5)	3.8 (2.7-5.5)	<0.001	3.96 (2.71-5.79)	<0.001
duration of disease (mean±SD)	21.8±8.15	18.0±7.5	1	<0.001	0.99(0.94-1.05)	0.823
higher education (high school + university)	36 (48.7%)	135 (61.4%)	0.6 (0.4-1.0)	0.056	1	1
comorbidity (Yes)	41 (54%)	93 (42.8%)	1.6 (0.95-2.7)	0.073	1	1

Table 2. Predictors for receiving a full exemption from copayment.

full exemption from co-payment	receiving	not receiving	univariate analysis	is	multivariate analysis	ysis
(N=224)	(%) u	(%) u	OR (95% IC)	p-value	OR (95% IC)	p-value
gender (M)	69 (30.8%)	16 (21.9%)	1.58 (0.85-2.97) 0.145	0.145	1.84 (0.90-3.78)	960.0
age (mean±SD)	51.1±10.9	44.6±8.1	1	<0.001	< 0.001 1.04 (1.0-1.08)	0.051
progressive course	78 (35.3%)	2 (2.7%)	19.4 (4.3-87.8)	<0.001	1	1
EDSS (median; IQR)	4.0 (2.0-6.5)	1.5 (1.0-2.5)	1	<0.001	<0.001 1.55 (1.31-1.85)	<0.001
duration of disease (mean±SD)	19.5±8.2	17.4±6.4	1	0.046	0.98 (0.93-1.03) 0.409	0.409
higher education (high school + university)	127 (57.2%)	44 (61.1%)	0.85 (0.49-1.47)	0.560	-	1
comorbidity (Yes)	102 (45.5%)	32 (43.8%)	1.07 (0.63-1.83)	0.800	-	1

Table 3 Risk factors for receiving a disabled badge.

Parking mark (N=95)	receiving	not receiving	univariate analysis	sis	multivariate analysis	ysis
	(%) u	n (%)	OR (95% IC)	p-value	OR (95% IC)	p-value
gender (M)	27 (28.4%)	58 (28.7%)	0.99 (0.6-1.7)	0.959	1.02 (0.46-2.30)	0.958
age (mean±SD)	52.4±10.9	48.1±10.3	-	0.001	1.0 (0.95-1.03)	0.675
progressive course	46 (48.9%)	34 (17.0%)	4.7 (2.6-8.4)	<0.001	1	1
EDSS (median; IQR)	6.5 (5.5-7.0)	2.0 (1.0-3.0)	-	<0.001	<0.001 2.36 (1.93-2.91)	<0.001
duration of disease (mean±SD)	20.4±8.5	18.3±7.5	1	0.040	0.97 (0.93-1.02)	0.253
comorbidity (Yes)	50 (52.6%)	84 (41.6%)	1.6 (0.95-2.6)	0.075	1	1
higher education (high school + university)	51 (53.7%)	160 (60.3%)	0.8 (0.5-1.3)	0.283	1	
not driving (Yes)	44 (46.8%)	31 (15.5%)	4.8 (2.7-8.7)	<0.001	0.73 (0.32-1.70)	0.472

Table 4 Risk factors for care allowance.

care allowance (N=38)	receiving	not receiving	univariate analysis		multivariate analysis	lysis
	(°/0) u	(%) u	OR (95% IC)	p-value	p-value OR (95% IC)	p-value
gender (M)	11 (28.95%)	74 (28.6%)	1.01 (0.48-2.16)	0.962	0.95 (0.35-2.58)	0.916
age (mean±SD)	55.5±10.0	48.6±10.5	1	<0.001	<0.001 1.0 (0.95-1.05)	996.0
progressive course	31 (81.6%)	49 (19.1%)	18.7 (6.9-50.7)	<0.001	ı	1
EDSS (median; IQR)	7.0 (6.5-7.5)	2.5 (1.3-5.0)	1	<0.001	3.57 (2.24-5.70)	<0.001
duration of disease (mean±SD)	22.6±7.6	18.4±7.8	1	0.002	1.0 (0.95-1.06)	0.878
comorbidity (Yes)	21 (55.3%)	113 (43.6%)	1.6 (0.8-3.2)	0.179	-	1
higher education (high school + university)	17 (47.2%)	154 (59.7%)	0.67 (0.32-1.40)	0.286	-	1

Table 5 Risk factors for allowed off work for medical reasons

allowed off work for medical	receiving	not receiving	univariate analysis	sis	multivariate analysis	lysis
reasons (n=79)	n (%)	(%) u	OR (95% IC)	p-value	OR (95% IC)	p-value
gender (M)	20 (25.3%)	65 (29.8%)	0.80 (0.44-1.43)	0.450	0.72 (0.35-1.49)	0.373
age (mean±SD)	49.1±8.9	49.6±11.2	1	0.700	0.94 (0.91-0.98)	0.001
progressive course	31 (39.2%)	49 (22.8%)	2.2 (1.3-3.8)	0.005		1
EDSS (median; IQR)	6.0 (2.5-7.0)	2.0 (1.0-5.0)	1	<0.001	1.71 (1.46-2.00)	<0.001
duration of disease (mean±SD)	19.8±7.4	18.7±8.0	1	0.269	1	1
higher education (high school + university)	52 (65.8%)	119 (55.4%)	1.6 (0.9-2.7)	0.107	2.21 (1.11-4.41)	0.025
comorbidity (Yes)	50 (63.3%)	84 (38.5%)	2.8 (1.6-4.8)	<0.001	2.85(1.50-5.43)	0.001
occupation (not employed+retired)	37 (46.8%)	80 (36.7%)	1.5 (0.9-2.6)	0.115	0.59 (0.26-1.35)	0.211

*Conflict of Interest/ Role of Funding Source

Conflict of interest

The Authors declare that there is no conflict of interest.

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