

PR MS Registry: MS Disability Survey

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ABSTRACT

Multiple sclerosis (MS) has a high incidence and prevalence in Puerto Rico (PR) with 6.3 (in 2014) and 70.1 per 100,000 respectively. The PRMS registry has been instrumental in the acquisition of data for the characterization of MS in PR. Law 85 was passed and it states that every physician authorized to practice medicine in PR has to register all their patients, with patient consent, to the PRMS registry. This law facilitates research on MS in Hispanics. Some of the data the registry offers sheds light on disability trends. This information can aid government agencies in acquiring the correct funds to better serve these patients. The aim of this study is to evaluate disability trends in PR Hispanics with MS. The PR MS Registry collects data from all diagnosed Puerto Rican MS patients living on the island. A self-reported questionnaire is collected from each patient. Clinical data is obtained from a neurologist. Data was analyzed using descriptive statistical analysis. MS subtype was analyzed for 1165 patients. Relapsing Remitting MS was attributed to 853 (73.22%), Secondary Progressive MS was seen on 246 (21.12%), Primary Progressive MS was present in 8(0.69%), Clinically Isolated Syndrome MS as diagnosed 55 (4.72%) patients, Radiologically Isolated Syndrome MS was only seen in 3 (0.26%) patients. EDSS scores were analyzed for 1078 MS patients. Patients with EDSS ≤ 3 were 62.62%, 3.5-6 were 21.61%, 6.5 \geq were 15.77%. Walking aid assistance was observed for 1515 patients. 60.86% of patients did not require walking aid, 30.69% of patients were currently using walking aid, and 8.45% had past use. Employment status for 1665 patients was analyzed. Working patients amounted to 36.64%, disabled 26.85%, retired 10.21%, housewife 13.51%, unemployed 8.59%, and student 5.53%. This data shows that there is a high percentage of these patients that are disabled and thus require governmental aid. This data shows the importance of the PRMS registry and how it can help establish disability and working status trends.

OBJECTIVE

Evaluate disability trends in PR Hispanics with MS.

METHODS

Data was collected from all diagnosed Puerto Rican MS patients living on the island. A self-reported questionnaire consisting of clinical, demographic, and diagnostic data is collected from each patient. Clinical data is obtained from a neurologist and MS diagnosis is confirmed using revised 2010 McDonald criteria. Patient information is collected at the moment of interview regarding patient status at that time. Data was analyzed using descriptive statistical analysis.

RESULTS

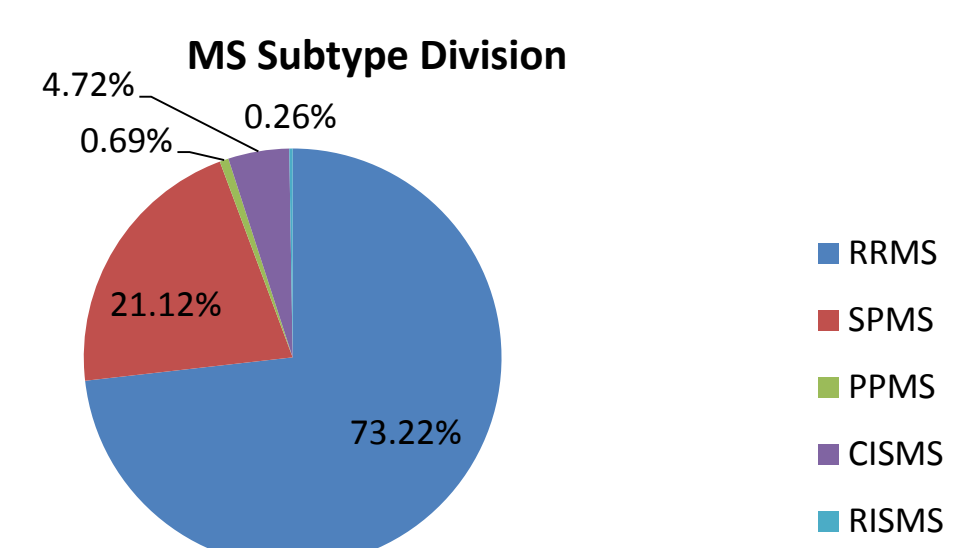


Figure 1: Division by percentage of MS subtype. Most abundant subtype is RRMS. Progressive MS accounted for 21.74% of the patient population.

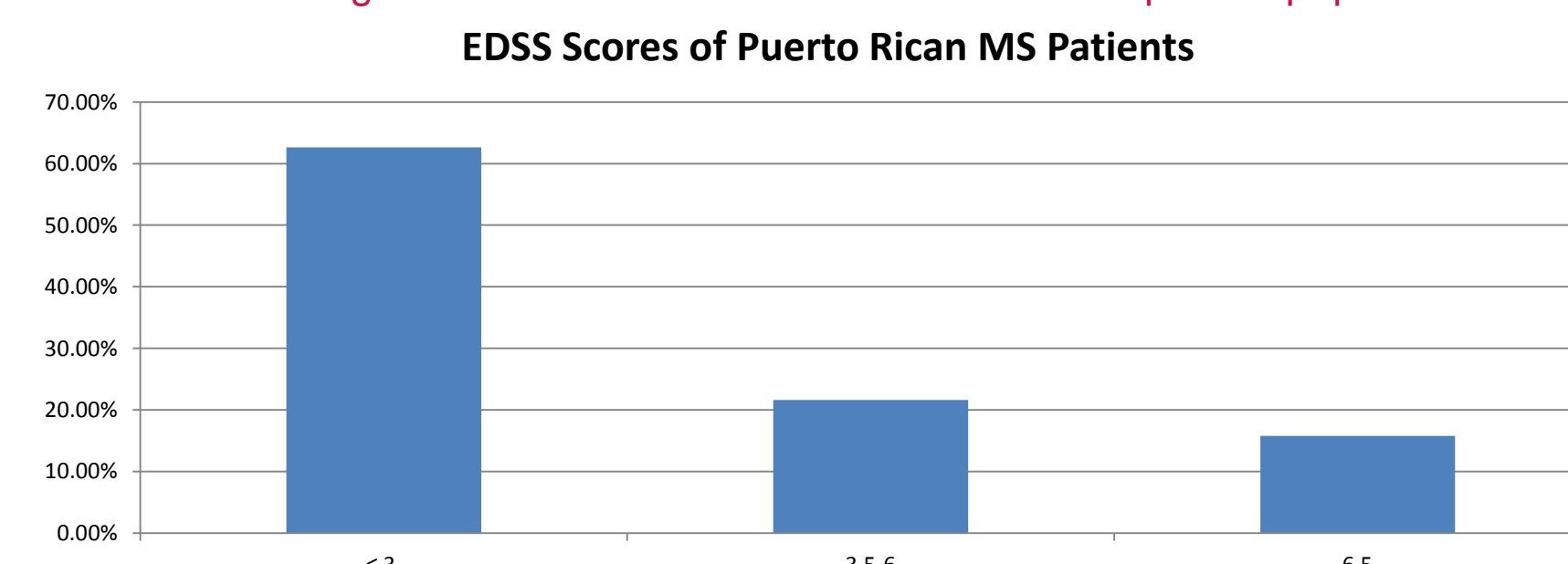


Figure 2: EDSS scores for the analyzed Puerto Rican MS patients divided by percentage.

Walking Status	Patients	Percentage
No Walking Aid	922	60.86
Current Walking Aid	465	30.69
Walking Aid Past Use	128	8.45

Table 1: MS patient that require or have required walking aid. The majority have never required walking assistance.

Disability Status of Puerto Rican MS Patients

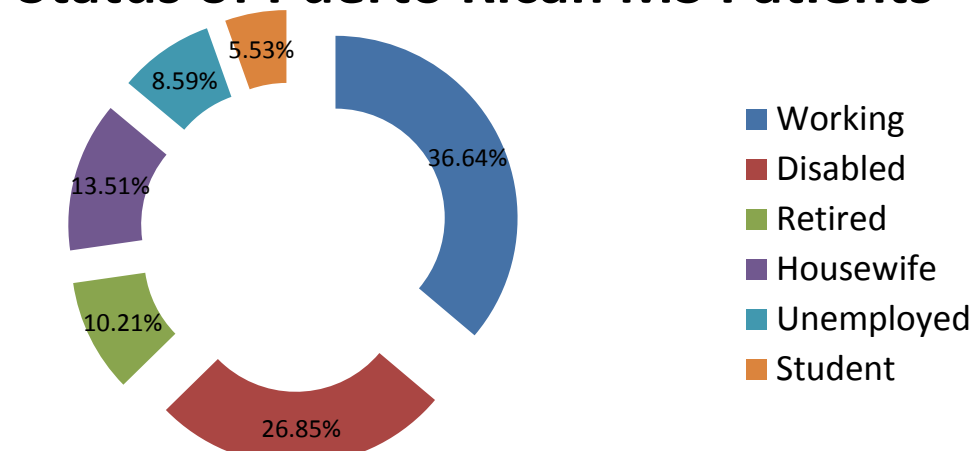


Figure 3: Distribution by percentage of disability status of Puerto Rican MS patients.

DISCUSSION

MS subtype was analyzed for 1165 patients. Relapsing Remitting MS was attributed to 853 (73.22%), Secondary Progressive MS was seen on 246 (21.12%), Primary Progressive MS was present in 8(0.69%), Clinically Isolated Syndrome MS as diagnosed 55 (4.72%) patients, Radiologically Isolated Syndrome MS was only seen in 3 (0.26%) patients. EDSS scores were analyzed for 1078 MS patients. 675 (62.62%) of patients presented EDSS ≤ 3 . EDSS of 3.5-6 was found in 233 (21.61%) individuals and EDSS of 6.5 \geq was found in 170 (15.77%). Walking aid assistance data was analyzed for 1515 patients. 922 (60.86%) of patients did not require walking aid, 465 (30.69%) of patients were currently using walking aid, and 128 (8.45%) had past use of walking assistance. Employment status for 1665 patients was analyzed. Working patients amounted to 610 (36.64%), disabled 447 (26.85%), retired 170 (10.21%), housewife 225 (13.51%), unemployed 143 (8.59%), and student 92 (5.53%).

CONCLUSIONS

The PRMS registry can be used to establish disability factors for MS patients. It is important to note that most PR MS patients are not disabled. However, this data shows that there is a high percentage of Puerto Rican MS patients that are disabled (26.85%) and/or do not have an important source of income (37.84%) (housewives, students, retired, and unemployed). Therefore, these patients require governmental aid. Many of the analyzed individuals require or have required walking aid assistance and many (21.74%) are in a progressive form of the disease. 37.38% of patient had a high EDSS rating, further establishing their rate of disability. The PRMS registry can be of use to the medical field as well as the government. This data shows the importance and usefulness of the PRMS registry and how it can help establish disability and working status trends.

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