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emsp EUROPEAN MULTIPLE SCLEROSIS PLATFORM

Assessing the employment status of people with MS across Europe

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Background & Objectives

A challenging consequence of Multiple Sclerosis (MS) is the economic burden since many patients need to quit working early because of MS related challenges. The PRO (Patient-Reported Outcomes) study of the EUReMS (European Register for Multiple Sclerosis) project focusses on the identification of differences in quality of life and employment between the participating MS registers.

Methods

Three registers have been elected to participate in the PRO study: the MS-Register der DMSG (Germany), the REJSM – Polish MS register (Poland) and the SMSreg - Svenska Multipel Skleros registret (Sweden). A total of 1965 patients met the study's inclusion criteria. Since SMSreg has been collecting PRO data for years, it contributed the largest amount of patients (n=1386). PRO data collection in Poland (n=245) and Germany (n=334) was started in 2013. Data collected up until summer 2014 was analysed. A data handling routine has been developed to process and harmonize the heterogeneous data of the three registers. To adjust for differences in baseline patient characteristics statistical analyses involve multivariable logistic regressions with employment status as outcome.

Results

	Country		
	GER	POL	SWE
Date of Data Export	01.08.2014	01.08.2014	11.08.2014
Number of PwMS	333	241	1338
% women	27.3 %	34.0 %	29.3 %
% relapse-remitting	47.1 %	40.6 %	73.3 %
% prim.-progressive	10.2 %	5.2 %	4.4 %
% sec.-progressive	42.6 %	54.1 %	22.3 %
Age of Onset (years)	32.5 (10.2)	34.8 (8.9)	31.5 (9.9)
Disease duration	15.4 (10.2)	13.5 (8.6)	12.9 (9.1)
MSIS-29 physical (median)	52.8	32.5	11.2
MSIS-29 psychol. (median)	50.0	38.9	19.4
EQ5D (median)	--	0.60	0.78
EDSS	4.8 (2.2)	4.0 (2.0)	2.8 (2.2)

Substantial differences in the employment rate were found between the registers ($p<0.001$). In Germany and Poland one third of the PwMS (People with MS) are employed, in Sweden more than 70%. The majority of the employed Pole has a progressive disease course. In Sweden 85% and in Germany 53% are relapsing-remitting. Of the unemployed PwMS the distribution of disease course is similar to that of the employed PwMS. In Germany, though, the progressive form of MS is now dominating (about 75%).

Discussion & Prospects

The data indicate how sensitive employment can be to underlying circumstances. A lot of progress has already been made to keep PwMS longer in employment, especially the Swedish MS register data show that high employment rates of PwMS are possible. One has to bear in mind, though, that Sweden has one of the lowest unemployment rates in the EU anyway and the collected data are from outpatients with a mostly RR-MS patient base. Findings of our study might also be slightly biased due to different definitions of income-generating work. Also selection biases may remain even after adjustment for covariates due to different data sources: E. g. in contrast to the Swedish outpatients, the analysed data of Germany was primarily collected at a rehabilitation centre with no clear representation of the work situation in Germany. The differences of the patient collective are especially visible in the MSIS-29 scores of the patients and the EDSS score which show the more „severe" cases are situated in the German dataset. The usage of a variety of data sources offers an underrated potential in assessing heterogeneity and sensitivity of result and should be further pushed. To efface the limited representaion of the few German and Polish data from that time of export, it is planned to update the data of those registers, as well as included UK data, and to repeat the analysis, trying to give a decided assessment of the employment status of PwMS across Europe.

Data providers for PRO Study

MS-Register der DMSG, Bundesverband e.V., GermanY; REJSM – Polish MS register, Poland; SMSreg – Svenska Multipel Skleros registret, Sweden

EUReMS PRO working group

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