

Employment outcomes in paediatric onset MS

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on behalf of the German Multiple Sclerosis Register by the German MS Society

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1. Background

Paediatric onset MS, defined by first symptom before the age of 18, often comes with high levels of disease activity. Life-threatening disease courses and so called break through MS are more common than in adult onset MS. Often relapses remitted completely, whereas neuropsychological deficits are more relevant compared to young adults.

2. Aims and Hypotheses:

This study aims to provide quantitative analyses on long-term employment outcomes and sociodemographic factors for paediatric onset MS in Germany.

3. Methods and Material:

- Data [export date: 13.08.2019] of 20,672 people with Multiple Sclerosis (PwMS) from the German MS-Register were analysed.
- Group comparisons were done using Fisher's exact test (p_F) for categorical data, t-test (p_t) for metric outcomes and Wilcoxon test (p_W) for ordinal outcomes considering p-values $p < 0.05$ statistically significant. No adjustments for multiple comparisons were made due to the exploratory nature of the study.
- Matched controls were obtained by optimal matching on gender and year of birth achieve an improved comparability of cohorts.

4. Results:

	Females (%)	Ø-Age (last visit)	Ø-Age at onset	Ø-Time to diagnosis (since 2010)
Paediatric onset MS (n=987)	78.8%	36.5 (±12.5)	15.8 (±2.0)	4.0 (median= 0.6)
Adult onset MS (987 matched cases)	78.8%	36.8 (±12.3)	25.0 (±2.6)	1.1 (median= 0.1)
Adult onset MS (n=19,671)	71.4%	48.1 (±11.8)	34.5 (±10.3)	1.8 (median= 0.2)

Table 1: Demographics (% , mean, and standard deviations) in years.

Only a very small proportion of PwMS has an onset below the age of 18. Considering all diagnoses in the MS-Register since 2010 only 2.8% had a paediatric onset of the disease (Fig1).

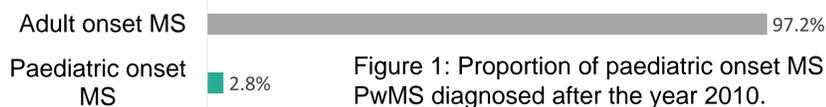


Figure 1: Proportion of paediatric onset MS in PwMS diagnosed after the year 2010.

The employment status of poMS is showing higher levels of unemployment. Less poMS finish professional (job) or university training.

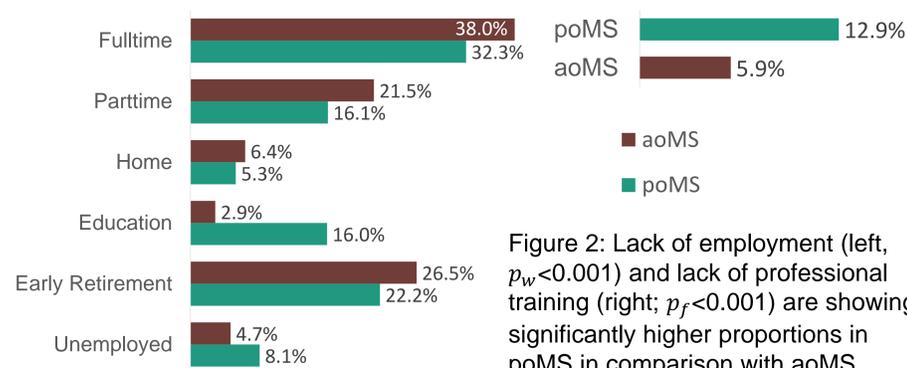


Figure 2: Lack of employment (left, $p_W < 0.001$) and lack of professional training (right; $p_F < 0.001$) are showing significantly higher proportions in poMS in comparison with aoMS.

5. Conclusions:

- Paediatric onsets are rare (2,8%), underreporting might be possible due to the fact that paediatric neurologists take care until the age of 18 years in Germany, and until now do not report to the MS-Register.
- Our analysis showed that patients with paediatric onset MS are significantly more often not able to finish a school degree, nor to work.
- While their EDSS does not show major impairment (after age 45) for most of them even after 25+ years disease duration their deficits are more neuropsychological which is reflected in the reduced numbers of finished school and job trainings.
- This may be due to the fact that MS afflicted a developing brain and highly effective therapy may be helpful to prevent these consequences.
- Male poMS seem to have much higher difficulties to find life partners.

	poMS	aoMS	poMS females	poMS males
University graduation (age 28+)	18.7%	19.1%	16.5%	26.7%
Not working (unempl. / early retir.)	30.3%	20.9%	30.7%	29.0%
Without partner	37.2%	34.2%	35.3%	44.2%
Support (by family and friends)	59.6%	59.9%	59.9%	58.6%

Table 2: Comparison paediatric vs. adult and female vs. male within poMS.

People with poMS are more likely to be alone and the effect is stronger in the male subgroup. However, in regard to university graduation a relatively large successful male poMS subgroup exists.

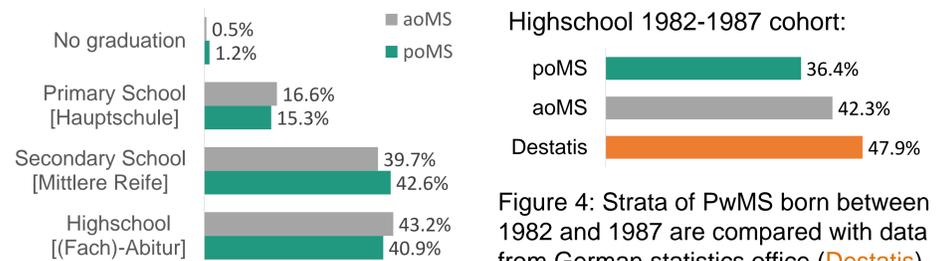
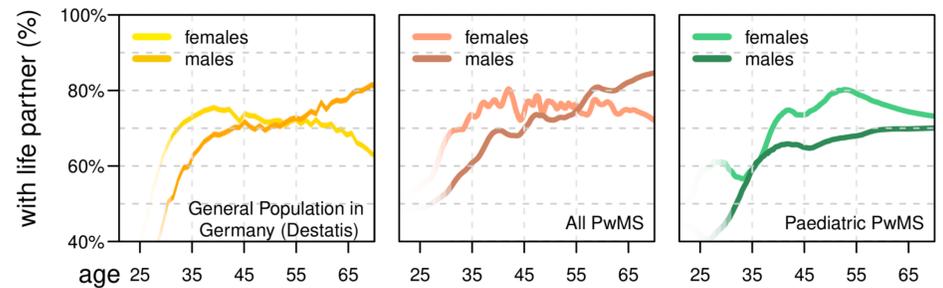


Figure 3: Distribution of achieved school education after at least 20 years of age

Highschool 1982-1987 cohort:



Figure 4: Strata of PwMS born between 1982 and 1987 are compared with data from German statistics office (Destatis) in regard to the proportions of achieved highschool graduation.



Figures 5: Proportion of being with a partner by age in the general German population (left), the German PwMS (centre), and the paediatric PwMS (right).

	poMS	aoMS	poMS females	poMS males
EDSS age 45-60 (n=193)	4.8 (±2.0)	4.5 (±2.2)	4.6 (±1.9)	5.2 (±2.1)
Severe (EDSS > 6) (%)	29.5%	28.4%	24.5%	45.7%
Progression Index	.23	.58	.23	.25
Prog. Ind. (brainstem)	.25	.58	.23	.29
Prog. Ind. (cerebellar)	.33	.60	.34	.30

Table 3: Disease progression, stratified by symptoms at onset.



Abstract References Download

Disclosure – Declaration of Interest

FF, OR: nothing to disclose
 PF has received speaker's fees and honoraria for advisory boards from Almirall, Bayer, Biogen, Genzyme, Merck-Serono, Novartis, Roche and Teva. He has participated in pharmaceutical company sponsored trials by Almirall, Biogen Idec and Novartis. None resulted in a conflict of interest.
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