

Patient reported perspectives on disease burden and early signs of progression in multiple sclerosis in Germany (data collection MSPerspectives)

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Conflict of interest

Bayas A.,
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EPR-159

- Antonios Bayas received personal compensation from Merck Serono, Biogen, Novartis, TEVA, Roche, Sanofi-Aventis/Genzyme, Celgene/Bristol-Myers Squibb and Janssen; he received grants for congress travel and participation from Biogen, TEVA, Novartis, Sanofi/Genzyme, Merck Serono and Celgene. None related to this report.
- Katrin Schuh is employee of Novartis Pharma GmbH, Germany
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- Discordant perception of the presence and severity of MS symptoms between healthcare professionals and people with multiple sclerosis (pwMS) may lead to an underestimation of symptom prevalence and relevance.
- Therefore, determining patients' perspectives is highly relevant for patient counseling and treatment decisions.
- In clinical practice, SPMS is usually diagnosed retrospectively and the transition period from RRMS to SPMS is associated with a considerable period of diagnostic uncertainty.
- For early detection of disease progression, it is imperative to raise patient awareness to recognize, track and communicate subtle signs of progression.
- The present large cross-sectional survey "MS Perspectives" was designed to collect data on patients' self-assessment of symptoms, the burden of the disease, disease progression, as well as the impact on daily activities.

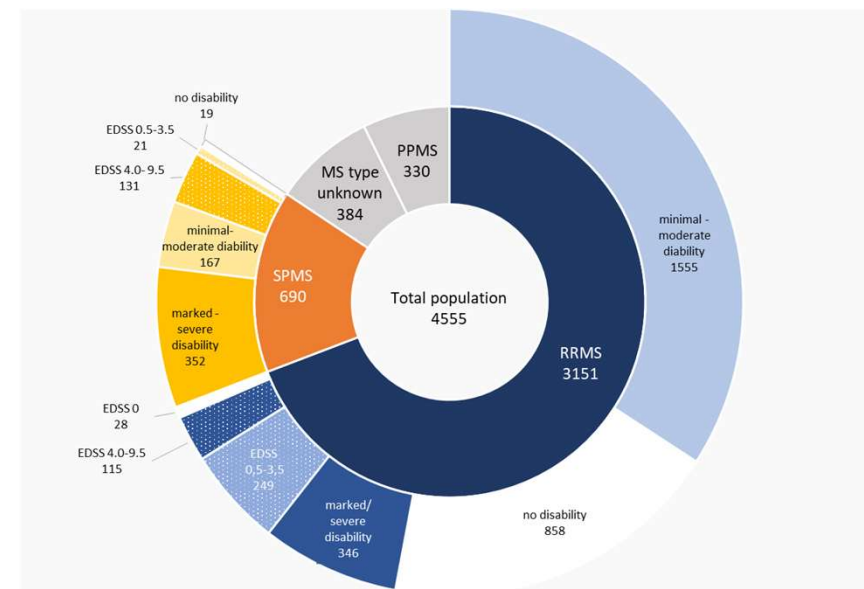


- MS Perspectives is a cross-sectional online survey conducted among adult pwMS in Germany between December 2021 and February 2022.
- Participants were identified through newsletters and targeted social media advertising in Germany.
- The questionnaire included 36 items on sociodemographic and clinical characteristics as well as pharmacological and non-pharmacological treatment including PwMS`s perceptions regarding MS symptoms, disability progression and impact on daily life.
- All data were analyzed descriptively. No formal statistical testing for group comparisons was performed.
- Data were handled confidentially.
- Anonymity of participants was secured throughout the study.



Demographics, MS subtypes and EDSS/ disability status

- 4,555 pwMS completed the survey: 3,151 (69.2%) reported to have RRMS, 690 (15.1%) SPMS, 330 (7.2%) PPMS, and 384 (8.4%) MS of unknown course
- 85.2% were female, with a higher proportion in RRMS (88.3%) than in SPMS subgroup (78.0%). Mean age was 41.6 years.
- In 13.5% of participants, EDSS was reported: mean (SD) EDSS was 3.8 (2.2) in the total population, 2.8 (1.8) RRMS, and 5.7 (1.6) SPMS
- 72.3% of the total population had no or mild to moderate disability, and 27.7% of patients marked to severe disability (defined either by EDSS score or self-assessment). Distribution was quite similar in RRMS subgroup (85.4% vs. 14.6%), in the SPMS subgroup most patients had marked to severe disability (30.0% vs. 70.0%)

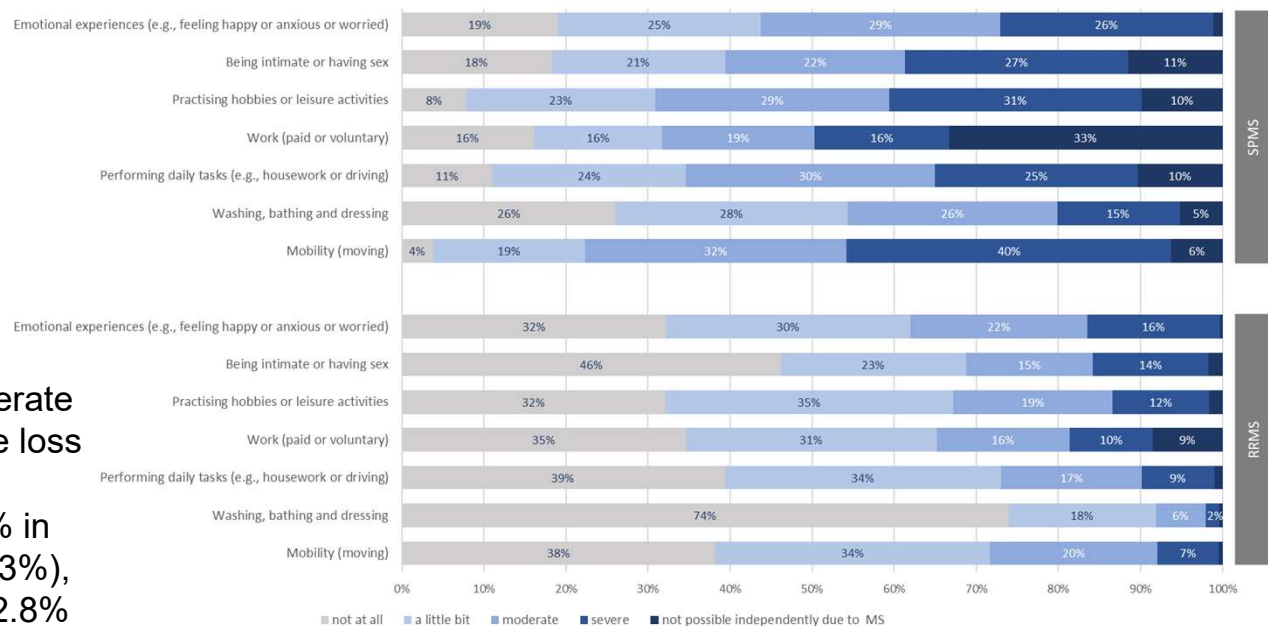


MS subtypes and EDSS/ disability status; figures in segments represent absolute patient numbers. Disability not indicated for unknown MS type and PPMS.



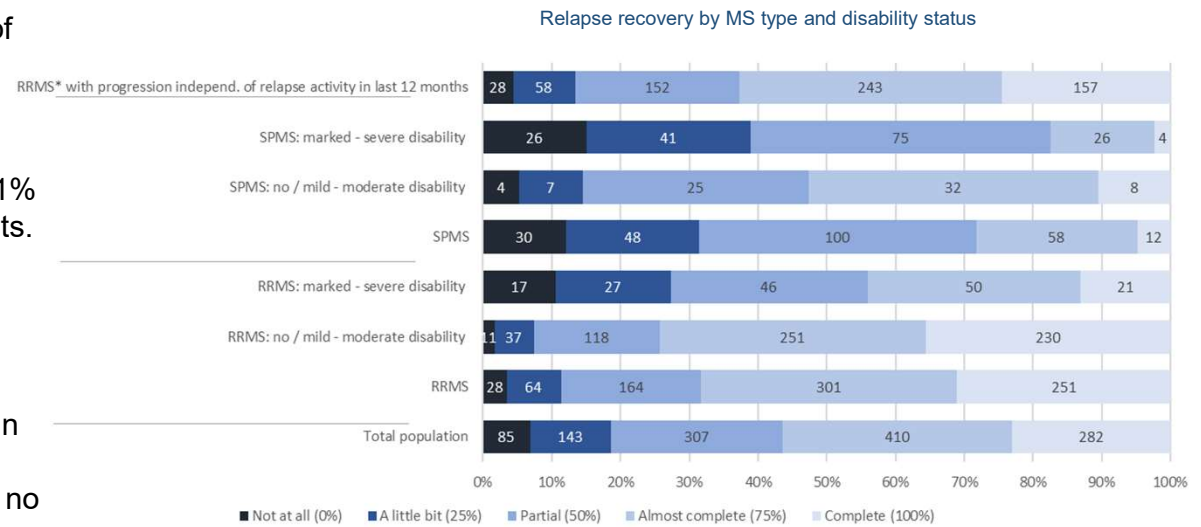
Impairment in activities of daily living by MS type

- 8.1% to 38% of RRMS patients reported moderate to severe impairment or complete loss of independence in daily activities assessed.
- In SPMS patients this was more prevalent with 45.7% to 77.7%.
- Marked differences regarding moderate and severe impairment or complete loss of independence were observed in mobility (28.3% in RRMS vs. 77.7% in SPMS), work ability (34.8% vs. 68.3%), and hobbies or leisure activities (32.8% vs. 69.1%)



Relapse recovery and presence of disease progression independent of relapse activity

- Relapse activity in the last 6 months was reported by 26.9% of total population, 25.6% of RRMS, and unexpectedly 35.9% of SPMS patients (not shown).
- Complete recovery from last relapse was achieved in 23% of the total population, in 31.1% of RRMS subgroup, and in 4.8% SPMS patients. Higher disability was associated with higher frequency of residual symptoms after the last relapse.
- Progression independent of relapse activity in the last 12 months affected 65.8% of patients in RRMS subgroup (in 88.9% of RRMS patients with marked to severe disability, in 61.8% with no or mild to moderate disability). In the SPMS subgroup this was more prevalent as reported by 92.9% of patients (in 95.2% of SPMS patients with marked to severe disability, in 87.4 with no or mild to moderate disability) (not shown).



*RRMS subtype according to patients' declaration in the survey; figures in bars represent absolute patient numbers.



- MS Perspectives gives an important insight in self-assessed MS symptoms and severity in a large-scale cohort which is highly representative for the MS population in Germany.
- As expected, impairment in daily activities was approximately two-fold higher in SPMS patients compared to RRMS. Mobility, hobbies or leisure activities, and work ability were the most strongly impaired activities among SPMS patients.
- Especially with regard to progression independent of relapse activity, the present data at least suggests that in a relevant proportion of RRMS patients, above all, but not only with marked to severe disability, a transition to SPMS may have already occurred but had not been recognized by the patient or healthcare professional.
- Regarding disease progression especially in patients still classified as RRMS, efforts should be made to increase awareness for SPMS transition in clinical practice, also with focus on less visible signs of progression.

