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A large cohort study evaluating patient reported perspectives on disease burden and early signs of progression in multiple sclerosis in Germany (MSPerspectives)

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Background: Secondary progressive multiple sclerosis (SPMS) is usually diagnosed retrospectively and the transition period is associated with a considerable period of diagnostic uncertainty. Therefore it is imperative to educate and raise patient awareness to recognize, track and communicate subtle signs of progression early on. The data collection presented (MSPerspectives) aims to comprehensively capture the patient perspective on the individual disease course.

Methods: MS Perspectives is a cross-sectional online survey conducted among adult MS patients in Germany between December 2021 and February 2022. The questionnaire included 36 items on sociodemographic and clinical characteristics as well as pharmacological and non-pharmacological treatment. The survey was designed to collect data on patients' self-assessment of MS symptoms, relapse-independent progression, and MS impact on everyday life. **Results:** Of 4,555 MS patients who completed the survey, 69.2% reported to have relapsing-remitting MS (RRMS) and 15.1% SPMS. Mean EDSS (when reported) was 2.6 in the RRMS population, 5.4 in the SPMS population and relapse activity in the past 6 months, was reported by 26.9% of the total population, 25.6% of RRMS patients, and 35.9% of SPMS patients. Relapse-independent worsening of symptoms was noted by 88.9% of RRMS patients with marked to severe and in 61,8% with no or mild to moderate disability. As most bothersome symptom, RRMS patients with marked to severe disability mentioned problems with walking (32.1%), whereas fatigue and cognitive problems were reported in RRMS patients with no or mild to moderate disability. **Conclusion:** MS Perspectives gives an important insight in MS symptoms and severity as well as treatment utilization in a large-scale cohort. 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.

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