

Discordance between neurologists and people with multiple sclerosis on the perception of the presence and burden of cognitive impairment

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OBJECTIVE

This study explores the perception of the presence of cognitive impairment (CI) from the perspectives of people with multiple sclerosis (pwMS) and neurologists

BACKGROUND

Approximately 34%-65% of pwMS develop CI. CI often encompasses information processing speed, memory problems, difficulty concentrating, and problems using executive functions effectively. Cognitive status relates to working ability of pwMS and may be predictive of a more aggressive disease course. CI is not routinely assessed in clinical consultations, and therefore can remain undetected

DESIGN/METHODS

US, UK and EU (France, Germany, Italy, and Spain) retrospective data analysis from the 2011-2019 Adelphi Multiple Sclerosis Disease-Specific Programme (MS-DSP). The MS-DSP is a database where neurologists provide data on the next 10 pwMS to have a consultation, patient record form (PRF), integrated with pwMS self-reported data, patient self-completion form (PSC). Both, pwMS and neurologists, were asked about the presence of problems concentrating recently.

RESULTS

25,374 pwMS had a PRF (68% females, mean age 40.4 years [SD 11.85]) (21,736 RRMS and 3,638 SPMS). 11,220 pwMS had a PRF and PSC, of these 4294 (3850 RRMS and 444 SPMS) answered the cognition section, with 62% (n=2,643) reporting CI (mild 36.8%, moderate 18.6, or extreme 6.1% problems concentrating) in the past two weeks. For the same pwMS, neurologists reported 27% (n=1,158) currently having CI (mild 19.9%, moderate 6.8%, or severe 0.3% problems concentrating), showing a discordance on the perception of the presence of CI between neurologists and pwMS (Kappa=0.162).

CONCLUSIONS

A clear discordance is observed between neurologists and pwMS when reporting their perception of the presence and severity of CI with neurologists clearly underestimating the existence. This might be responsible for cognition not being discussed at the time of consultation and clearly indicates an unmet need.