Differences in physician and patient perspectives on patients' burden related to hidden symptoms of multiple sclerosis

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BACKGROUND

- Multiple Sclerosis (MS) is a demyelinating disease of the central nervous system[1] with a variable clinical course characterized by neurological dysfunction and progressive disability
- MS patients experiencemultiple manifestations during the disease course that include not only physical symptoms but also hidden symptoms such as fatigue, depression, anxiety, and cognitive problems, which can be difficult to communicate, recognize, detect, and monitor

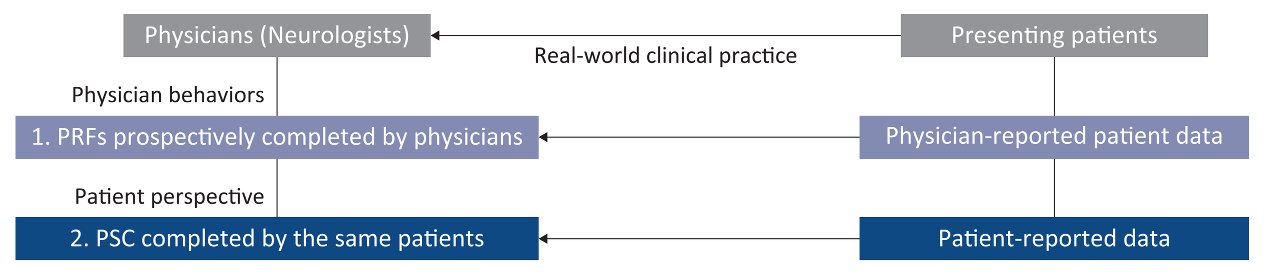
OBJECTIVE

- To identify areas of alignment and differences between patients and their physicians on reporting MS severity and hidden symptoms

METHODS

- This study used data from the Adelphi MS Disease Specific Program™ (DSP), a cross-sectional survey with validated methodology and that collected data from neurologists and MS nurses (in the UK only) and their MS patients in the US (n=1546), Italy (n=880), Germany (n=881), Spain (n=661), France (n=675), and the UK (n=714), with a total base of 5357, between December 2020 and June 2021. The full DSP methodology has previously been published[3] (**Figure 1**)
- Physicians completed online patient record forms (PRFs) reporting on their consulting patient's current level of MS disease severity ('*How would you describe the severity of the patient's MS?*') and symptoms ('*Please indicate the status of the current symptom*'). Patients also reported their current level of disease severity ('*How would you rate the severity of your MS?*'), and experience of their MS symptoms ('*Because of my MS, during the past 4 weeks I have…*')
- The focus for this analysis was on mental-health related symptoms (e.g. fatigue, mood, cognition) that are not obvious and unapparent to physicians, referred to as 'hidden symptoms'

Figure 1. Adelphi DSP methodology



DSP, disease specific program; PRFs, patient record forms; PSC, patient self completion forms.

- Study population included patients currently diagnosed with a relapsing form of MS: relapsing-remitting MS (RRMS) or secondary-progressive MS (SPMS)-active (patients with SPMS that have experienced 1≥ relapse in the last 12 months)
- Inclusion criteria:
  - Patients who were aged 18 or older
  - Not currently involved in a clinical trial
  - Current diagnosis of relapsing MS
- Frequency of disease severity level and symptoms reported by physicians and patients along with level of agreement between both reporters using kappa-statistic is reported (**Table 1**)

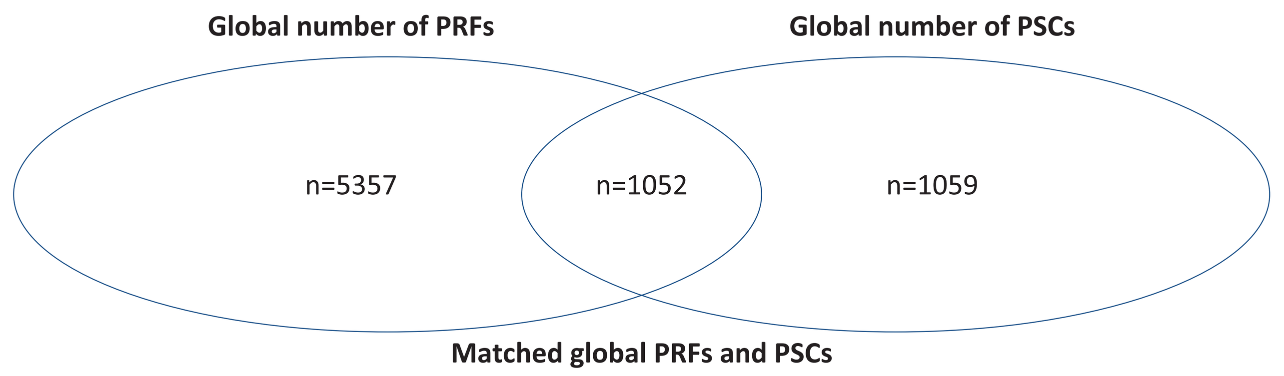
Table 1: Kappa statistic measure of agreement[4]

Kappa output	Agreement level
Below 0.00	Poor
2 0.00–0.20	Slight
2 0.21–0.40	Fair
0.41–0.60	Moderate
0.61–0.80	Substantial
0.81–1.00	Almost perfect

RESULTS

- 1052 matching PRFs and PSCs of physicians and their consulting patients with RRMS were available for analysis (**Figure 2**)

Figure 2. Venn diagram to show the bases for individual and matched questionnaire types



PRF, patient record form; PSC, patient self completion form.

- Physicians and patients were moderately aligned on the degree of patient's disease severity (Cohen's kappa =0.443); the highest frequency differential was for severe where more patients rated themselves as severe compared with physicians (**Table 2**)

Table 2: Physician and patient alignment on disease severity, n (%)

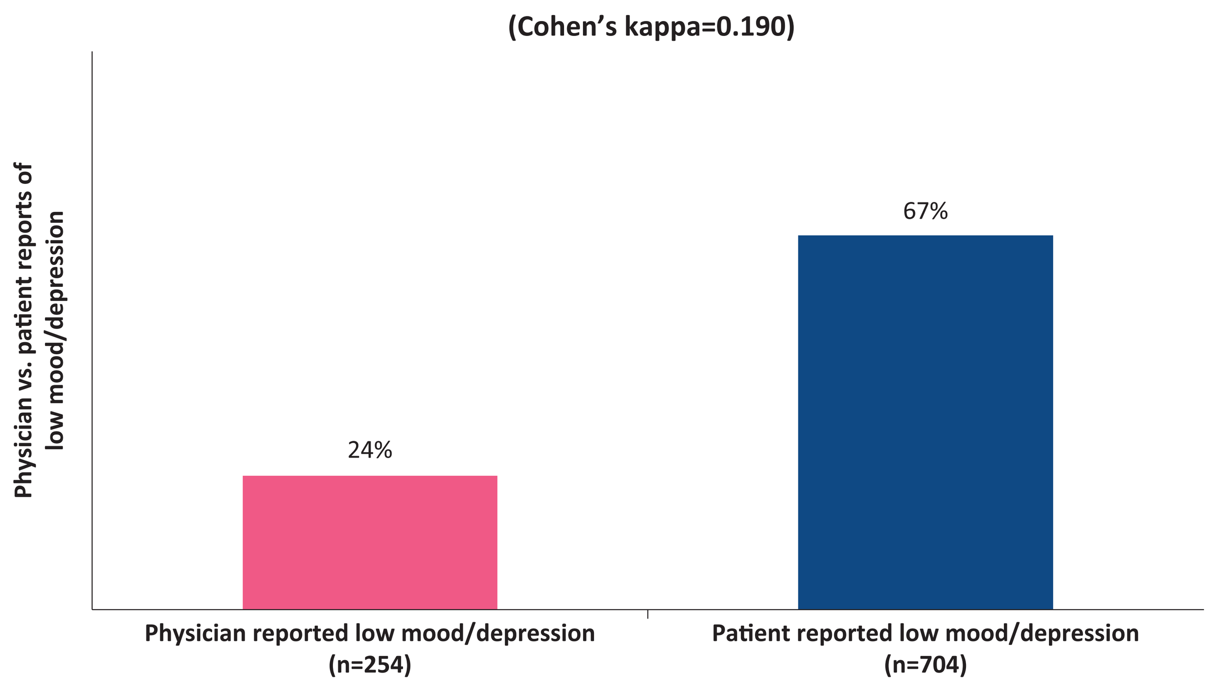
Severity level	Physician reported % of patient severity	Patient reported % of patient severity	Cohen's kappa measure of agreement
Very mild	29% (n=300)	23% (n=245)	0.443
Mild	45% (n=475)	177/528 (33.52%)	
Moderate	24% (n=251)	24% (n=250)	
Severe	2% (n=26)	15% (n=163)	

- Physicians substantially underestimated the presence of hidden MS symptoms in their patients

Mood

- Physicians reported 24% (n=254) of their patients experiencing feeling low/depressed whereas 67% (n=704) of patients reported feeling these symptoms with slight agreement (Cohen's kappa =0.190) (**Figure 3**)

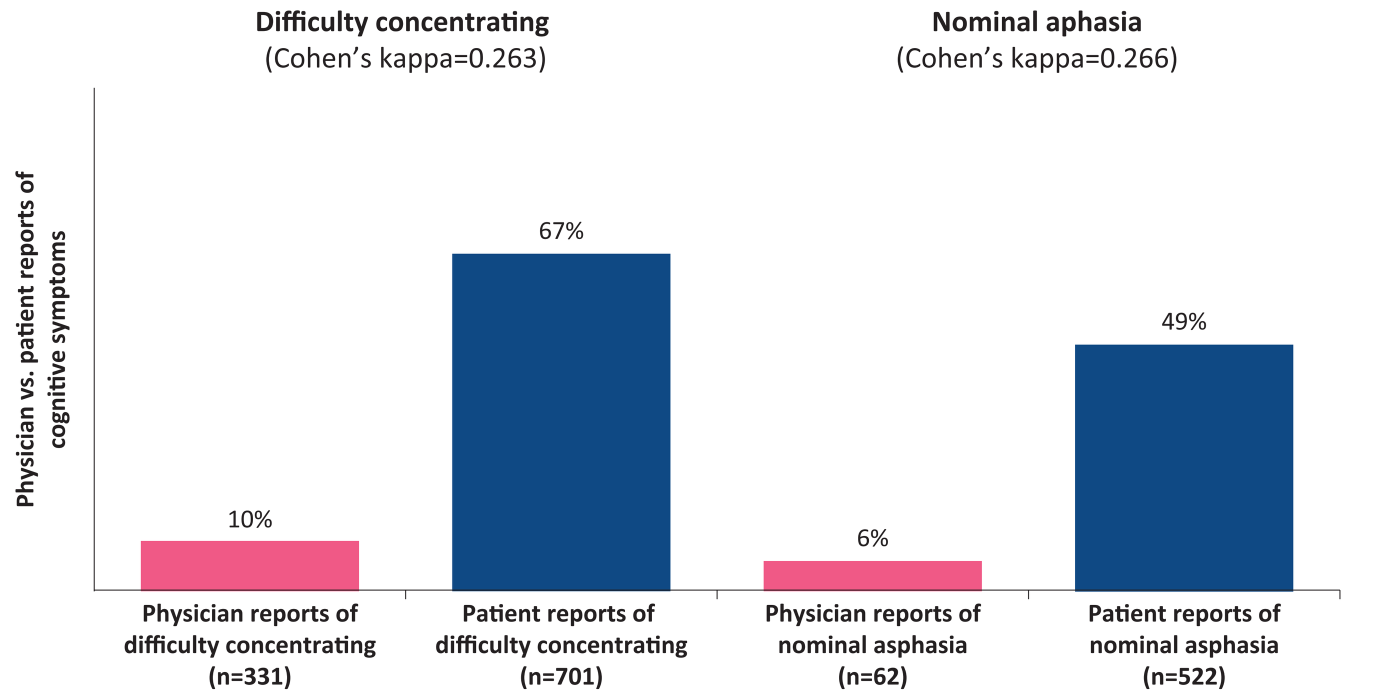
Figure 3. Physician vs patient reporting of patient's experience of low mood/depression



Cognition

- Physicians reported only 10% (n=331) of their patients experiencing difficulty concentrating, whereas 67% (n=701) of patients reported feeling this with fair agreement (Cohen's kappa=0.263) (**Figure 4**)
- Differences were also observed for nominal aphasia (problems recalling names and words), as physicians reported that 6% (n=62) of their patients experience this but 49% (n=522) of patients reported this symptom

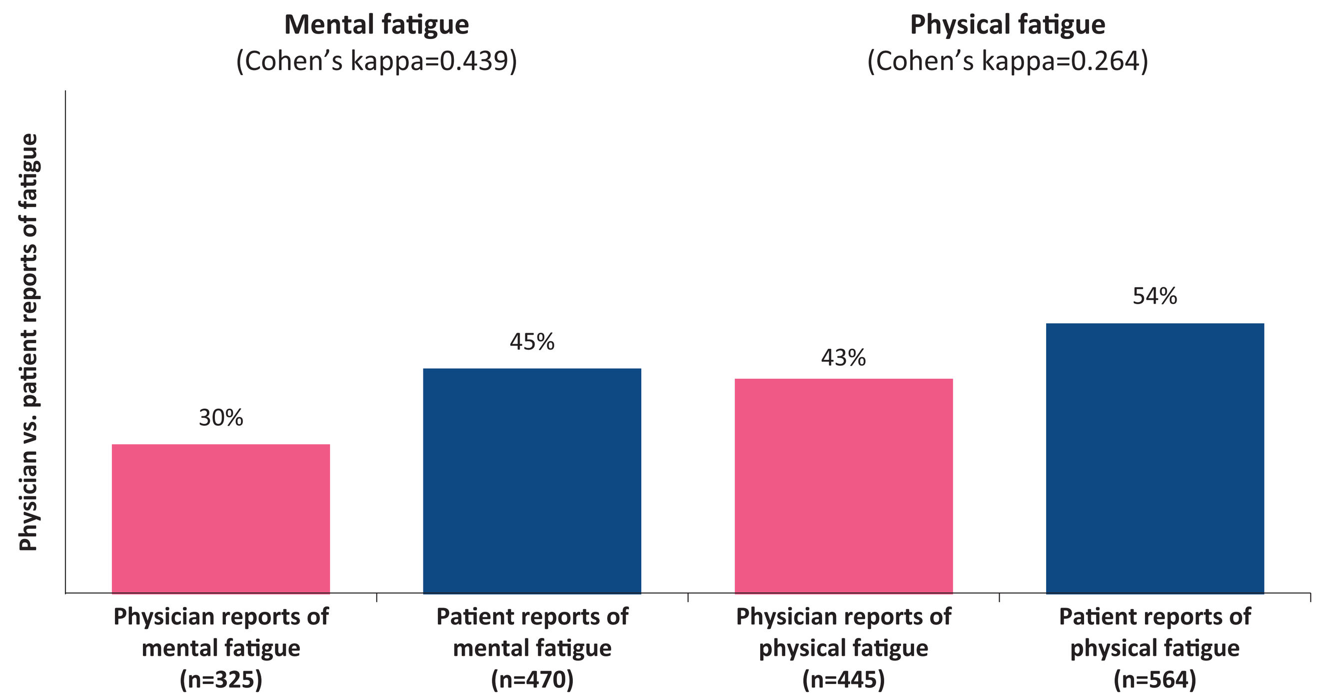
Figure 4. Physician vs patient reporting of patient's experience of cognitive symptoms



Fatigue

- There was moderate agreement on mental fatigue with physicians reporting 30% (n=325) of their patients experienced mental fatigue whereas 45% (n=470) of patients reported experiencing this hidden symptom (**Figure 5**, Cohen's kappa =0.439)
- Physicians reported 43% (n=445) of their patients reported physical fatigue and 54% (n=564) patients reported experiencing this symptom (**Figure 5**), with fair agreement (Cohen's kappa=0.264)

Figure 5. Physician vs patient reporting of patient's experiencing fatigue



LIMITATIONS

- Identification of the target patient group (relapsing forms of MS) is based on the judgement of the responding physician and not a formalized diagnostic checklist but is representative of physician's real-world classification of the patient
- The point-in-time design of this study prevents any conclusions about causal relationships; however, identification of significant associations is possible
- Cohen's kappa statistical test assumes lower estimates of agreement excessively, which may underrate the level of agreement seen in reality between physician's and patient's assessment of disease severity

CONCLUSIONS

- Physicians and their patients with relapsing MS are moderately aligned on disease severity. The difference in rating was largely observed for severe MS where more patients (15%) rated their MS as severe than their physicians (2%)
- More patients reported experiencing hidden symptoms compared to physicians reporting hidden symptoms for their patients with poor to fair agreement on mood, cognitive symptoms and physical fatigue; agreement was moderate for mental fatigue
- These findings highlight the importance of a collaborative discussion between physicians and their patients and that allows patients to vocalize all symptoms they currently experience, including those that are not apparent to, or raised by, the physician
- Such, all-inclusive discussions can help physicians also consider their patients' perspectives in optimizing treatment approaches in addressing needs of their patients with MS

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Disclosures

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