

Background

- Daytime sleepiness in the general population is associated with reduced quality of life (QOL), lower job performance and increased risk of accidents. It can also be a symptom of obstructive sleep apnea (OSA), a serious condition and a contraindication for certain medications.
- Previous reports on sleep disturbances in small MS samples suggest that both daytime sleepiness and OSA are common.

Objective

- To establish the prevalence of self-reported sleep disturbances and daytime sleepiness in a large MS population and assess symptoms and factors associated with the most severe cases.

Methods

- The North American Research Committee on MS (NARCOMS) operates a large voluntary self-report registry for people diagnosed with MS. Participants are asked to complete a questionnaire at enrollment and semi-annually thereafter. The registry currently contains data submitted by over 37,000 people over a period of 25 years.
- We analyzed responses to sleep-specific questions administered to NARCOMS Registry participants in 2009 in conjunction with the routine semi-annual survey that assesses disability status using Patient Determined Disease Steps (PDDS) and Performance Scales (PS), and QOL using the Short-Form 12 (SF12).
- Sleep-specific questions included the Epworth Sleepiness Scale (ESS), diagnosed sleep disorders including OSA and insomnia, and the Berlin questionnaire.
- Group comparisons were based on the total score on the ESS (range 0-32), where a score ≥ 9 indicates clinically relevant daytime sleepiness and a score of ≥ 16 is considered severe.
- We linked the responses with previously collected background information and analyzed the dataset using descriptive statistics.

TABLE 1 Demographic and Clinical Characteristics of the responders by ESS classification

	ESS 0 – 8 (sub-clinical) N=5283	ESS 9 – 15 (clinically relevant) N= 1981	ESS 16 – 32 (severe) N=449	ALL responders N=7713
Women	76.9 %	78.3 %	77.9 %	77.0%
Men	23.1%	21.7%	22.1%	23.0%
Race (% white)	91.7%	91.7%	88.6%	91.9%
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Age in 2012	55.4 (10.5)	55.4 (10.6)	56.5 (10.0)	55.4 (10.5)
Disease duration	16.8 (9.7)	16.5 (9.9)	16.5 (9.5)	16.7 (9.8)
Body Mass Index (BMI)	26.0 (6.8)	27.6 (8.2)	28.5 (7.8)	26.5 (7.4)
SF 12 PCS	37.8 (11.7)	34.5 (11.0)	30.6 (9.5)	36.5 (11.6)
SF 12 MCS	48.1 (11.2)	44.2 (11.5)	39.6 (11.8)	46.6 (11.6)
	Median [IQR]	Median [IQR]	Median [IQR]	Median [IQR]
PDDS (0 to 8) *	4 [1, 6]	4 [2, 6]	5 [3, 7]	4 [1, 6]
Fatigue (0 to 5) **	2 [1, 3]	3 [2, 4]	4 [3, 4]	3 [2, 4]
Snoring	52.6%	63.1%	60.9%	55.9%
Periodic limb movements	33.0%	46.1%	53.7%	37.7%
Falling asleep while driving	5.2%	14.4%	30.8%	9.1%
ESS Total (range 0 – 32)	0 - 8	9 – 15	16 – 24	0 – 24
Diagnosed with insomnia	6.5%	19.2%	23.2%	17.6%
• of them, treated	69.4%	66.1%	56.7%	67.8%
Diagnosed with OSA	5.0%	10.2%	15.4%	6.9%
• of them, treated	64.2%	64.0%	65.2%	63.9%
Diagnosed with depression	33.7%	47.3%	47.9%	38.3%
• of them, treated	83.8%	85.8%	81.6%	84.2%

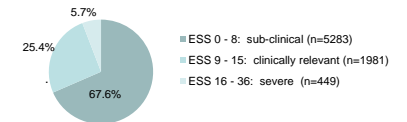
*Patient Determined Disease Steps (PDDS) disability levels: 0= normal 1= mild 2= moderate 3= gait disability
4=early cane 5= late cane 6= bilateral support 7= wheelchair/scooter 8= bedridden

**Performance Scale disability levels: 0 = normal 1= minimal 2= mild 3= moderate 4= severe 5=total

Results

- The 7713 participants who completed the sleep-related section of the survey were predominantly white (91.9%) and women (77%). On average (SD) they were 55.4 (10.5) years old and had a disease duration of 16.7 (9.8) years. Their median [IQR] PDDS score was 4 [1, 6] and PS fatigue score 3 [2, 4]. TABLE 1
- 4309 (55.9%) reported snoring and 2906 (37.7%) periodic limb movements. As many as 9.1% percent of the responders admitted having nodded off or fallen asleep while driving, although only 173 (2.2%) reported a frequency of once or twice a month or more.
- Almost a third (31.5%) scored ≥ 9 on the ESS, including 449 (5.8%) with a score ≥ 16 . FIGURE 1
- Despite similar age and disease duration, the ≥ 16 group had higher PDDS disability and PS fatigue score than those scoring below 9, and scored considerably lower in both physical and mental domains of the SF12 (PCS and MCS). The severe ESS group was also more likely to report snoring, periodic limb movements and nodding off or falling asleep while driving. TABLE 1
- Despite the prevalence of reported symptoms, only 24.6% of all responders had a medical diagnosis of either insomnia (17.6%) or OSA (7.0%). About one out of three of those diagnosed with insomnia or OSA were not treated for that condition. TABLE 1
- Depression was reported by 2957 responders (38.37%); it was more common among the severe ESS group than the lower scoring groups. Overall, 84.2% of those diagnosed with depression were receiving treatment. TABLE 1

FIGURE 1 Distribution of ESS sleepiness scores



Conclusions

- Sleep disturbances and daytime sleepiness are common in MS and potentially under-treated.
- Severe cases are associated with higher levels of disability and lower QOL in both physical and mental domains.
- Further studies are needed to address the role of lifestyle choices and the potentially sedating effect of medication as contributing factors in daytime sleepiness.