

# How do neurologists perceive the organization and functioning of multiple sclerosis care units?

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## Abstract

This study assessed how neurologists perceive the organization and functioning of multiple sclerosis care units. As a cross-sectional, observational study conducted in collaboration with the Spanish Society of Neurology, an electronic survey of 116 neurologists revealed that 39.7% of participants identified a need for improvement in their unit's care processes based on the Care Process Self-Assessment Tool (CPSET). The primary areas for improvement were collaboration with primary care and patient follow-up. A significant negative correlation was observed between lower CPSET scores and a higher prevalence of clinician occupational stress ( $p = 0.035$ ), with 28.4% of neurologists reporting burnout. These findings suggest that enhancing care coordination could improve care delivery for patients and help mitigate the risk of burnout for clinicians.

**Keywords:** Multiple sclerosis, neurologists, organization, care unit, multidisciplinary care, burnout

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## Introduction

Effective organization and coordination of care are essential for achieving high-quality outcomes in the management of multiple sclerosis (MS).<sup>1,2</sup> The growing complexity of therapeutic options and care pathways in MS has made well-structured and collaborative MS units essential.<sup>2–4</sup> Initiatives such as the European Charcot Foundation's MS Care Unit (MSCU) survey aimed to map access to specialist care and set standards for multidisciplinary clinics.<sup>5</sup> Deficiencies in care delivery not only impact patient outcomes but can also lead to occupational stress and burnout in healthcare professionals.<sup>6</sup> This study aimed to evaluate neurologists' perceptions of the organization and functioning of care within their MS units.

## Methods

This cross-sectional, observational study was conducted as part of the NewFeeLS-MS project in collaboration with the Spanish Society of Neurology (SEN).<sup>7</sup> The overarching NewFeeLS-MS project was designed to investigate the role of serum

neurofilament light chain testing in informing treatment decisions in MS care, as this was one of the many variables collected in the study. The current analysis is an evaluation of neurologists' perceptions of the quality of care processes in their respective MS units, which was a secondary, pre-specified objective of the project. The study was approved by the ethical review board of Hospital Universitario Clínico San Carlos, Madrid, Spain, and all participants provided written informed consent.

Neurologists who treat MS patients were invited by the SEN to participate in an electronic survey between August and December 2023. The survey collected information on demographic and professional background, behavioral traits, and workplace characteristics.<sup>7</sup> The Care Process Self-Assessment Tool (CPSET) was used to measure participants' perception of the quality of the MS care process.<sup>8</sup> This included five subscales: patient-focused organization, coordination, collaboration with primary care, communication with patients and family, and follow-up. The questionnaire consists of 29 items scored on a

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**Table 1.** Demographic, professional, and behavioral characteristics of participants.

	N = 116
Age, years, mean (SD)	41.9 (10.1)
Sex, male, <i>n</i> (%)	62 (53.4)
Professional experience, years, median (IQR)	14.0 (8.0–23.0)
Caring for MS, years, median (IQR)	10.0 (5.0–18.0)
Type of hospital, academic, <i>n</i> (%)	110 (94.8)
Number of MS patients/week, median (IQR)	16.0 (10.0–25.0)
Attendance atECTRIMS congress, <i>n</i> (%)	104 (89.7)
Co-author of peer-reviewed manuscripts, <i>n</i> (%)	64 (55.2)
Investigator in MS clinical trials, <i>n</i> (%)	63 (54.3)
Access to sNfL testing, <i>n</i> (%)	40 (34.5)
CPSET score, mean (SD)	6.2 (1.5)
Patient-focused organization	6.7 (1.9)
Coordination of care	7.1 (1.4)
Communication with patients and family	6.4 (1.8)
Collaboration with primary care	4.9 (2.0)
Follow-up of care	5.8 (1.8)
EBPAS score, mean (SD)	2.8 (0.4)
JSE-HP score, mean (SD)	107.7 (12.2)
RIS-10 score, mean (SD)	2.1 (0.8)
Open workplace communication,* <i>n</i> (%)	78 (67.2)
Burnout,** <i>n</i> (%)	33 (28.4)
Sick leave in the last year, <i>n</i> (%)	13 (11.2)

CPSET: Care Process Self-Evaluation Tool; EBPAS: Evidence-Based Practice Attitude Scale; IQR: interquartile range; JSE-HP: Jefferson Scale of Empathy-Health Professionals; MS: multiple sclerosis; RIS-10: Regret Intensity Scale-10; SD: standard deviation; sNfL: serum neurofilament light chain.  
\*Thriving from work questionnaire, cutoff score  $\geq 4$ .  
\*\*Physician work life study single-item, cutoff score  $\geq 3$ .

10-point scale, ranging from 1 (totally disagree) to 10 (totally agree), with higher scores indicating a better perception of the care process. An overall score below the 40th percentile was used to indicate a perceived need for improvement. The correlation between CPSET scores and occupational burnout was analyzed using Pearson's correlation coefficient.

## Results

A total of 116 neurologists participated in the study. The mean age of the participants was 41.9 (standard deviation (SD) 10.1) years, with 53.4% being male (Table 1). Most of the neurologists (94.8%) were based in academic hospitals, with a median of 10.0 (interquartile range 5.0–18.0) years of experience in MS care. A 28.4% ( $n = 33$ ) acknowledged experiencing burnout, and 11.2% ( $n = 13$ ) reported a sick leave in the last year.

The mean overall CPSET score was 6.2 (1.5). Notably, 39.7% of the neurologists ( $n = 46$ ) perceived

the MS care in their units as suboptimal. The subscale analysis identified collaboration with primary care (mean score: 4.9 [2.0]) and patient follow-up (mean score: 5.8 [1.8]) as the most critical areas for improvement (Table 1). A significant negative correlation was found between lower CPSET scores and a higher prevalence of burnout ( $r = -0.20$ ; 95% confidence interval:  $-0.37, -0.01$ ;  $p = 0.035$ ).

## Discussion

This study found that 39.7% of neurologists perceived a need for improvement in their unit's care processes. The most significant areas for improvement were identified as collaboration with primary care and patient follow-up. A significant negative correlation was observed between lower care process scores and a higher prevalence of occupational burnout. This suggests that enhancing care coordination could not only improve care delivery for patients but also help mitigate the risk of burnout for clinicians.

These findings from a specific national context align with broader international efforts to define and assess MS care quality. A recent progress report from the Italian Multiple Sclerosis Foundation and the European Charcot Foundation on the MSCU survey, which collected data from 147 institutions worldwide, identified key components of a “gold standard” care unit, including the presence of three core professionals (neurologist, nurse, and physiotherapist), the maintenance of an MS registry, and the use of patient-reported outcomes measures.<sup>5</sup> These findings were further echoed in a 2023 study on MS centers in Central–Eastern Europe, which found persistent shortages of specialties such as speech therapists and pain specialists, reinforcing a homogeneous pattern of shortcomings across different regions.<sup>4</sup> A systematic review supported the importance of a multidisciplinary team, including neurologists, nurses, physiotherapists, occupational therapists, and psychologists, in optimizing patient outcomes.<sup>9</sup> Our findings on the perceived shortcomings in primary care collaboration and follow-up reinforce this need for a more integrated, team-based approach to address the disease’s multifaceted nature and improve care coordination.<sup>10</sup>

Our study also contributes to the growing body of literature on physician burnout in neurology.<sup>6,11</sup> A recent survey including 136 MS neurologists from the United States found that approximately 50% of the respondents were experiencing burnout or its early signs.<sup>6</sup> Long working hours and the burden of maintaining electronic medical records (EMRs) were the most significant contributors to this burnout. EMRs were a source of frustration for 74% of respondents, with 61% reporting high levels of stress related to their use. These administrative burdens replace valuable patient interaction time, which can diminish a physician’s job satisfaction and sense of purpose.

As a survey-based study, it relies on participants’ understanding and interpretation of the questions, which can introduce a source of reporting bias. Another limitation is the lack of detail in the findings from the CPSET. While the study identified collaboration with primary care and patient follow-up as the most critical areas for improvement, the survey did not delve deeper into the precise reasons for these deficiencies. Within the Spanish healthcare system, these issues may be structurally driven by fragmented EMR systems that inhibit seamless data exchange between specialized MS units and primary care, or by a lack of standardized communication protocols

for co-managing patients and ensuring timely follow-up. Resource constraints that limit dedicated time for primary care physicians to coordinate complex MS care, or a shortage of specialized MS nurses, roles essential for optimizing follow-up and enhancing cross-disciplinary collaboration, could also contribute to these deficiencies. Furthermore, the study did not collect data on the disability level of the patients treated by the participating neurologists, nor did it assess the neurologists’ comfort or expertise in managing systemic comorbidities or internal medicine issues in MS patients.

In conclusion, our findings reinforce the importance of a truly multidisciplinary approach to MS care, which includes robust collaboration with primary care and an optimized patient follow-up process. Enhancing care coordination and follow-up could serve a dual purpose: not only improving care delivery for patients with MS but also mitigating the risk of burnout for the clinicians who treat them. Future research is needed to explore specific interventions that could strengthen these areas of care and assess their impact on both patient and provider outcomes.

#### Author note

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#### Conflict of Interests


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