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# Preferences Toward Attributes of Disease-Modifying Therapies: The Role of Nurses in Multiple Sclerosis Care

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## ABSTRACT

**BACKGROUND:** Nurses play an essential role in coordinating the care of patients with multiple sclerosis (MS) throughout their disease trajectory in a complex treatment landscape. The aim of this study was to assess nurses' preferences toward different disease-modifying therapy attributes. **METHODS:** We conducted a multicenter, noninterventional, cross-sectional study in collaboration with the Sociedad Española de Enfermería Neurológica. Nurses actively involved in MS care were invited to participate in the study. Prevention of disability progression, preservation of cognitive function, side effect profile and safety monitoring, and method of administration were the treatment attributes tested. Conjoint analysis was used to assess preferences in 8 simulated treatment options and rank them from most to least preferred. **RESULTS:** A total of 98 nurses were included in the study. The mean (SD) age was 44.7 (9.8) years, and 91.8% were female with a mean (SD) time of experience in MS care of 7.5 (5.4) years. Participants prioritized preservation of cognition (38.6%), followed by preventing disability progression (35.2%) and side effect risk and safety monitoring (13.5%). Route and frequency of administration were the least preferred attributes (7.4% and 5.3%, respectively). Estimated utilities were consistent across the sample according to sociodemographic and professional practice characteristics. **CONCLUSIONS:** Nurses' preferences toward treatments were mainly driven by efficacy attributes. This information may support the role of nurses in the multidisciplinary management of MS facilitating shared decision making.

**Keywords:** conjoint analysis, disease-modifying treatments, multiple sclerosis, nursing research, treatment preferences

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Multiple sclerosis (MS) is a chronic autoimmune disease of the central nervous system that mainly affects young people and is associated with physical and cognitive impairment and loss of functional autonomy.<sup>1,2</sup> The spectrum of disease-modifying therapies (DMTs) has grown substantially in the last 10 years, allowing for individualized disease management and more ambitious therapeutic goals.<sup>3,4</sup> In this context, nurses have an essential role in identifying the perceptions and needs of patients and caregivers at all stages of the disease according to the Neuman system model.<sup>5,6</sup> They usually participate in patient education and aspects related to disease care as well as on how treatments are administered, the importance of adherence, and potential side effects.<sup>5–11</sup> In addition, their close and frequent interaction with patients gives them the opportunity to detect more subtle symptoms that are often overlooked in follow-up office visits by neurologists.<sup>12,13</sup>

Although nurses cannot prescribe DMTs, understanding their treatment preferences and priorities may help to improve their role in a complicated treatment landscape with different side effect profiles and safety monitoring needs.<sup>3,14</sup> The aim of this study was to assess nurses' preferences toward relapsing-remitting MS treatments according to different attributes of efficacy, safety, and mode of administration.

## Methods

This is a multicenter, noninterventional, cross-sectional, Web-based study conducted in collaboration with the Sociedad Española de Enfermería Neurológica. Nurses with experience managing MS patients received an email from the Sociedad Española de Enfermería Neurológica with the invitation to participate in the study. This email included a link to access the study website. This study was approved by the Hospital Universitario Clínico San Carlos (Madrid, Spain) research board. A written informed consent was obtained from all participants.

Conjoint analysis is a well-established and validated approach to assess the value that people allocate to the different characteristics of medical interventions.<sup>15,16</sup> Preference elicitation using conjoint analysis has been studied in MS involving different healthcare professionals and patients.<sup>17–19</sup>

Treatment attributes and levels were originally designed by our research team of 7 nurses specialized in MS after reviewing clinical trials and patient preference research literature.<sup>14,19,20</sup> Prevention of disability progression, preservation of cognitive function, route and frequency of administration, and side effect risk and safety monitoring were the 5 attributes selected (Supplemental Digital Content 1, available at <http://links.lww.com/JNN/A420>). An orthogonal design was applied

to design 8 simulated treatment options containing unique combinations of attributes and levels (Supplemental Digital Content 2, available at <http://links.lww.com/JNN/A421>). Participants ranked treatment options from 1 (most preferred) to 8 (least preferred).

In addition, participants had to answer questions related to sociodemographic and professional practice characteristics, and completed questionnaires to measure nurses' attitude toward the adoption of medical innovations, coping strategies, workplace burnout, and healthcare-related regret.<sup>21–24</sup> The Evidence-Based Practice Attitude Scale is a high-psychometric-quality instrument used to measure attitudes toward adopting new treatments, interventions, and practices among healthcare providers.<sup>21</sup> It consists of 15 items rated on a 5-point Likert-type scale, ranging from 0 (not at all) to 4 (to a very great extent). Higher scores indicate a more positive attitude toward innovations. The Brief-COPE is a validated 28-item questionnaire designed to measure effective and ineffective ways to cope with a stressful life event.<sup>22</sup> Higher scores indicate increased utilization of the specific coping strategy. Occupational burnout was assessed using the 9 items of the emotional exhaustion dimension of the Maslach Burnout Inventory-Human Services Survey.<sup>23</sup> A score of 27 or greater indicates high emotional exhaustion. The 10-item Regret Intensity Scale is a validated tool used to assess regret caused by a past event, covering affective, physical, and cognitive aspects.<sup>24,25</sup> Higher scores indicate higher regret intensity.

## Statistical Analysis

The ordinary least squares method was used to estimate parameters. Results were summarized in terms of utilities (profits), relative (overall), and individual importance assigned to each attribute. The Kendall correlation coefficient between real ranges and those predicted by the model was used to assess the goodness of fit of the model. The relative importance of each factor was obtained by dividing the importance of a factor by the sum of all individual importance scores. A model fits the data well if the differences between the observed values and the predicted values are small and unbiased. The closer the coefficient is to 1, the better the model.

An exploratory *k*-means cluster analysis based on individual profits to different attributes was used to identify possible profiles of nurses with similar preferences. Differences in sociodemographic and professional practice characteristics as well as behavioral factors were assessed between clusters.

## Results

Overall, 331 nurses were invited to participate, 130 initiated the study (39.3%), and 98 completed the study (29.6%). The mean (SD) age was 44.7 (9.8) years,

**TABLE 1.** Demographic and Professional Practice Characteristics of the Sample

		<b>N = 98</b>
Sex	Female, n (%)	90 (91.8)
Age, y	Mean (SD)	44.7 (9.8)
	>40, n (%)	65 (66.3)
Work experience, y	As a hospital nurse, mean (SD)	21.1 (9.9)
	Managing patients with MS, mean (SD)	7.5 (5.4)
Work setting	Outpatient clinic, n (%)	48 (49.0)
	IV center, n (%)	33 (33.7)
MS patients managed per week	Mean (SD)	23.9 (22.6)
Training and professional activities	Participation in MS clinical trials, n (%)	61 (62.2)
	Authorship of scientific manuscripts/abstracts in peer-reviewed journals/congresses, n (%)	73 (74.5)
	Attendance to MS training activities in the last 2 y, n (%)	89 (90.8)

Abbreviations: IV, intravenous; MS, multiple sclerosis.

and 91.8% were female. Almost 50% worked at a hospital-based outpatient clinic with a mean (SD) time of experience managing MS of 7.5 (5.4) years. Main demographic and professional practice characteristics are shown in Table 1.

Treatment option E was the most chosen by the participants. Nurses prioritized the preservation of cognition (38.6%), followed by preventing disability progression (35.2%) and side effect risk and safety

monitoring (13.5%). Similar values were obtained with average importance (Table 2). Preserving cognition and preventing disability progression also were the most preferred attributes according to the utilities scores (Table 2). Overall, mode of administration was the least preferred attribute, although self-administration and administration over longer periods were the most valued in these 2 dimensions. Pearson *R* and Kendall  $\tau$  coefficients showed a high correlation: 1000 ( $P < .001$ )

**TABLE 2.** Utility Scores and Importance Assigned to Each Attribute and Level

	Utility Estimation (SE)	Importance (Relative)	Importance (Averaged)
Cognition			
No cognitive impairment	1.245 (0.040)	38.6%	32.7%
Cognitive impairment	-1.245 (0.040)		
Disease progression			
No progression in 2 y	1.133 (0.040)	35.2%	31.7%
Progression in 2 y	-1.133 (0.040)		
Safety and nurse monitoring			
Infrequent but severe AE plus monitoring 1–2 times a month	-0.434 (0.040)	13.5%	14.2%
Frequent but mild-moderate AE plus monitoring every 3–6 mo	0.434 (0.040)		
Route of administration			
Self-administered	0.240 (0.040)	7.4%	10.0%
Hospital administration	-0.240 (0.040)		
Frequency of administration			
At least twice a month	-0.143 (0.053)	5.3%	11.4%
Monthly	-0.056 (0.062)		
Every 6 mo	0.199 (0.062)		

Abbreviation: AE, adverse effect.  
Positive values indicate a greater preference for an attribute.

and 1000 ( $P < .001$ ), respectively. Estimated utilities were consistent across the sample according to socio-demographic and professional practice characteristics.

Two participant clusters were identified based on the prioritization assigned to each attribute. Cluster 1 included 78 (79.6%) nurses prioritizing treatments that preserve cognition and prevent disability progression. Cluster 2 included 20 nurses prioritizing route and frequency of administration of treatments. Cluster 1 participants showed a higher intensity of regret compared with cluster 2 participants (mean [SD] 10-item Regret Intensity Scale score, 2.2 [0.9] and 1.6 [0.7], respectively;  $P = .01$ ) (Supplemental Digital Content 3, available at <http://links.lww.com/JNN/A422>). Cluster 2 nurses managed a higher mean rate of MS patients per week compared with patients with other neurological diseases than cluster 1 participants (58.5% and 42.6%, respectively;  $P = .04$ ) and also showed a higher level of denial (mean [SD] Brief COPE denial score, 1.9 [2.1] and 0.9 [1.2], respectively;  $P = .008$ ) (Supplemental Digital Content 3, available at <http://links.lww.com/JNN/A422>). No other differences in demographic, professional practice, and behavioral characteristics were found between groups.

## Discussion

Current management of MS poses many challenges for healthcare professionals.<sup>5,6,26</sup> By focusing on coordinating the care of MS patients throughout the disease trajectory, nurses can capture different types of information and support neurologists in the treatment decision-making process.<sup>5,6,27,28</sup>

In this study, preserving cognition and delaying disability progression were the most chosen DMT attributes among nurses with experience managing MS in Spain. The importance of understanding perspectives toward MS DMTs has been explored mainly in patients.<sup>19</sup> Research on treatment preferences among healthcare professionals caring for MS has been less studied. Tencer et al<sup>29</sup> found that reducing the rate of brain volume loss was the most important treatment attribute among 101 neurologists from the United Kingdom, followed by risk of infections and progression of disability at 2 years. Delaying disease progression was the most prioritized treatment attribute in a study involving 65 hospital pharmacists in Spain, followed by preserving quality of life and cognition.<sup>18</sup>

There are very few studies of therapeutic goals aimed at understanding the perspective of nurses caring for MS patients, and they are mainly oriented toward their perception of tolerability of different drugs and advantages of autoinjectors.<sup>30–32</sup> Pélouquin et al<sup>8</sup> investigated knowledge and attitudes regarding MS care among 135 nurses from France, Germany, Italy, Spain, Canada, United States, and the United Kingdom. Participants

reported knowledge gaps on new DMTs available (51%), treatment sequencing (46%), and detection of treatment failure (52%). Most participants also reported difficulties interpreting certain neurological assessments and outcomes (eg, Timed 25-Foot Walk Test, no evidence of disease activity, no evidence of progression or active disease).<sup>7</sup> In a study with nurses and neurologists from the Netherlands, risk of life-threatening or severely disabling adverse events was the most important attribute in treatment decision, followed by effects on disability, frequency of relapses, and quality of life.<sup>17</sup> Both groups did not differ significantly in their perspective about which attributes were most important for making decisions, with statistical differences only being found in 2 low prioritized attributes (costs were ranked higher by neurologists and drug interactions were ranked higher by nurses).<sup>17</sup>

These results show that all healthcare professionals involved in MS care in Spain are aligned on the increasing importance of impacting disease progression with the goal of preventing disability. In our study, we found that a subset of nurses (20.4%) prioritized route and frequency of administration as the most important attributes of treatments. They had a higher rate of MS patients managed per week and a higher coping component of denial compared with those participants who prioritized efficacy attributes. We hypothesize that a higher workload may have influenced this preference for treatment options that are easier to administer and/or have lower safety monitoring requirements.

Our study has limitations that deserve mention. First, the limited availability of studies on treatment preferences in MS nurses determined that the selection of treatment attributes and levels in this study was based primarily on previous studies conducted in patients and neurologists. Second, the selection of few treatment attributes to avoid complex study design and difficulty in selecting preferences could have caused omitted variable bias owing to exclusion of additional key attributes already identified in previous studies, such as the relapse prevention rate.<sup>33</sup> Third, nurses are not the final decision-makers in prescribing MS treatments, and we have not captured their knowledge of the different efficacy and safety characteristics of currently available agents. Finally, nurses may have different responsibilities and activities in MS care depending on the country where they work. Therefore, these results may not necessarily be representative in other countries.

## Conclusion

This study showed that preserving cognitive function and reducing disability progression are the most valued DMT attributes among nurses caring for patients with MS. The understanding of nurses' preferences



may support their role in the multidisciplinary management of MS facilitating shared decision making by patients and neurologists.

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