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Wearing-Off Effect Towards the End of Treatment Cycles in MS Patients Receiving High-Efficacy Dmts – Data from Social Media Listening

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Abstract Text:

Background:

The experience of symptoms like fatigue, mobility issues and physical pain towards the end of treatment cycles – generally referred to as the wearing-off effect (WOE) – have been reported in the literature for patients living with multiple sclerosis (PlwMS) receiving infusible disease-modifying treatments (DMTs). While studies utilizing clinical and patient-reported outcome (PRO) measures indicate that WOE does not impact disease control, patients on social media have reported an impact of WOE on their quality of life (QoL).

Objectives:

To explore how various stakeholders (PlwMS, caregivers (CGs), health-care practitioners (HCPs) and advocacy groups) describe the symptoms, timing, coping strategies, and impact on QoL of WOE while being treated with various DMTs (natalizumab, ocrelizumab, ofatumumab, rituximab).

Methods:

Publicly available posts related to WOE on social media, blogs and forums were retrospectively reviewed. WOE-specific posts in English and posted between 1 Feb 2020 and 16 Feb 2022, authored by key stakeholders were analyzed. Relevant posts were identified through a specific search term-based funneling methodology.

Results:

Overall, 43,834 posts related to broader MS and WOE were identified; 730 conversations were WOE-specific, with 725 authored by PlwMS or CGs. Of these 725 posts, 535 were related to experiencing WOE and 277/535 posts mentioned WOE-associated symptoms. The most commonly reported WOE durations were 2–4 weeks with fatigue being the most mentioned symptom, followed by mobility issues and physical pain. In 374/535 posts, the treatment was specified and 9% of these posts mentioned an impact on QoL, such as need for more down time, interference with work, and difficulty walking. WOE coping strategies mentioned by patients included switching to other DMTs, reducing intervals between cycles, and taking steroids/other medications. WOE-related conversations by HCPs and advocacy groups were minimal throughout the listening period (4 and 1 posts, respectively).

Conclusions:

This exploratory study of social media posts found mentions of WOE by patients receiving DMTs were common, as were reports of WOE-related symptoms impacting QoL. Factors such as differing durations of DMTs in the market and number of patients using any specific therapy mean observations of social media conversations are prone to an inherent bias. Further research is required to understand the impact of WOE on PlwMS and the potential gap between HCP and patient perceptions/awareness of WOE.

Title:

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Category:

Disease-modifying therapy

Would you give CMSC and International Journal of MS Care the first preference to any article that is submitted for publication based on this abstract presentation?:

No

Late Breaking Reason:

A social listening study was conducted to better understand the patients' perception of WOE and its impact on QoL.

Category: Disease-modifying therapy

Keywords:

Disease-modifying treatments in MS and Wearing-off effect

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