Poster PCR177

Assessing the impact of relapses on patient outcomes in neuromyelitis optica spectrum disorder

Martin Kleman[1], Sarrina Tursunova[1], JT Tibung[1], Karl-Johan Myren[1], Mia Unsworth[2], Giorgio Castellano[2], Emily Trenholm[2], Nikisha Grant[2], Laura Le Brocq[2], Kristie Fitzmaurice[2]

1 Alexion, AstraZeneca Rare Disease
2 Adelphi Real World, Bollington, UK

INTRODUCTION

- Neuromyelitis optica spectrum disorder (NMOSD) is a rare, complement-mediated, autoimmune disease characterised by unpredictable relapses which often attack and permanently damage the spinal cord and optic nerve.
- NMOSD relapses are severe and have a cumulative, detrimental physical and psychological impact on patients.
- As NMOSD is a life-long disease, it is important to understand the real-world impact of NMOSD relapses on patient outcomes.

OBJECTIVE

- To assess how NMOSD relapses impact patient outcomes in a real-world setting.

METHODS

- Data were drawn from the Adelphi Real World NMOSD Disease Specific Programme (DSP)™. The DSP is a cross-sectional, multinational survey of physicians and their patients conducted in routine clinical practice to describe patient demographics and clinical characteristics, medical history and symptoms of NMOSD.
- Data collection was conducted in Italy, Germany, Spain, France, and the UK, between January 2023 and June 2023.
- The aim of the DSP is to facilitate understanding of real-world clinical practice. No tests, investigations or treatments were performed or prescribed as part of the survey.
- Physician inclusion criteria:
  - Neurologist
  - Actively involved in the management and treatment of at least 1 patient with AQP4+ NMOSD
- Patient inclusion criteria:
  - Patients who were aged 18 or older
  - Not currently involved in a clinical trial
  - Current diagnosis of AQP4+ NMOSD
- Descriptive analysis with significance testing was performed comparing outcomes in patients reported to have experienced a relapse versus not experienced a relapse since their initial NMOSD attack.

RESULTS AND INTERPRETATION

- Physician-reported data were available for 433 patients with NMOSD.
- 128 patients (30%) were reported by their physician to have experienced a relapse; 305 (70%) had not experienced a relapse since their initial attack.
- Patients were predominantly white females and those who experienced a relapse were older and had been diagnosed with NMOSD for longer than patients who had not (Table 1).

Table 1. Patient demographics and disease characteristics of patients with NMOSD who experienced relapse since their initial NMOSD attack compared to patients who did not experience a relapse

	Total (n=433)	Patients who experienced a relapse (n=128)	Patients who have not experienced a relapse (n=305)
Patient age (years)			
Mean (SD)	41.8 (12.24)	44.6 (12.18)	40.6 (12.10)
Median (range)	41.0 (18-80)	43.5 (18-75)	39.0 (18-80)
Patient sex, n (%)			
Female	276 (64%)	80 (62%)	196 (64%)
Patient ethnicity, n (%)			
White	306 (85%)	100 (90%)	206 (82%)
Black, African or Caribbean	28 (8%)	5 (5%)	23 (9%)
East or Southeast Asian	9 (2%)	1 (1%)	8 (3%)
South Asian	12 (3%)	3 (3%)	9 (4%)
Middle Eastern or North African	7 (2%)	1 (1%)	6 (2%)
Other	2 (1%)	1 (1%)	1 (<1%)
Time since diagnosis (years)			
Mean (SD)	3.7 (4.50)	5.2 (5.22)	3.1 (4.01)
Median (range)	2.1 (0-24.5)	3.4 (0-24.5)	1.3 (0-22.9)
Number of relapses since the initial NMOSD attack, n (%)			
0	305 (70%)	N/A	305 (100%)
1	82 (19%)	82 (64%)	N/A
2	24 (6%)	24 (19%)	N/A
3+	22 (5%)	22 (17%)	N/A
Time since most recent relapse (years)			
Mean (SD)	3.4 (4.08)	3.4 (4.08)	N/A
Median (range)	1.9 (0-24.0)	1.9 (0-24.0)	N/A

NMOSD, Neuromyelitis Optica Spectrum Disorder, SD, standard deviation, N/A, not applicable

- Patients most recent EDSS score was higher for those who had experienced relapse compared to patients who had not (Figure 1).
- Compared with patients who had not experienced a relapse, a higher number of patients who had experienced relapse were, at the time of the survey, experiencing: muscle weakness, muscle atrophy, back pain, bladder control deficit, bowel control deficit, nociceptive deficit and tactile deficit (Figure 2).
- More patients who had relapsed were also experiencing blindness, Uhthoff's phenomenon, seizures, and neck pain with movement, compared patients who had not (Figure 3).
- More patients who had experienced a relapse were consulting with a physiotherapist, urologist and a neuropsychologist compared to patients who had not experienced a relapse (Figure 4).

Figure 1. Most recent mean EDSS score of patients who have relapsed since their initial NMOSD attack vs patients who do not have a physician-reported relapse.

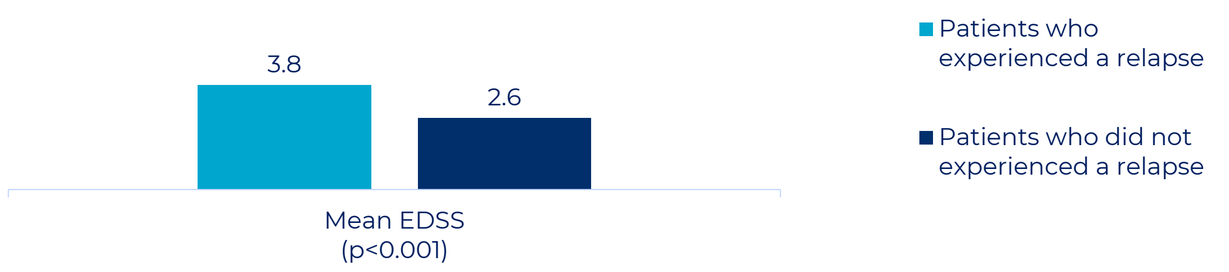


Figure 2. Myelitic symptoms of patients who have relapsed since their initial NMOSD attack vs patients who do not have a physician-reported relapse.

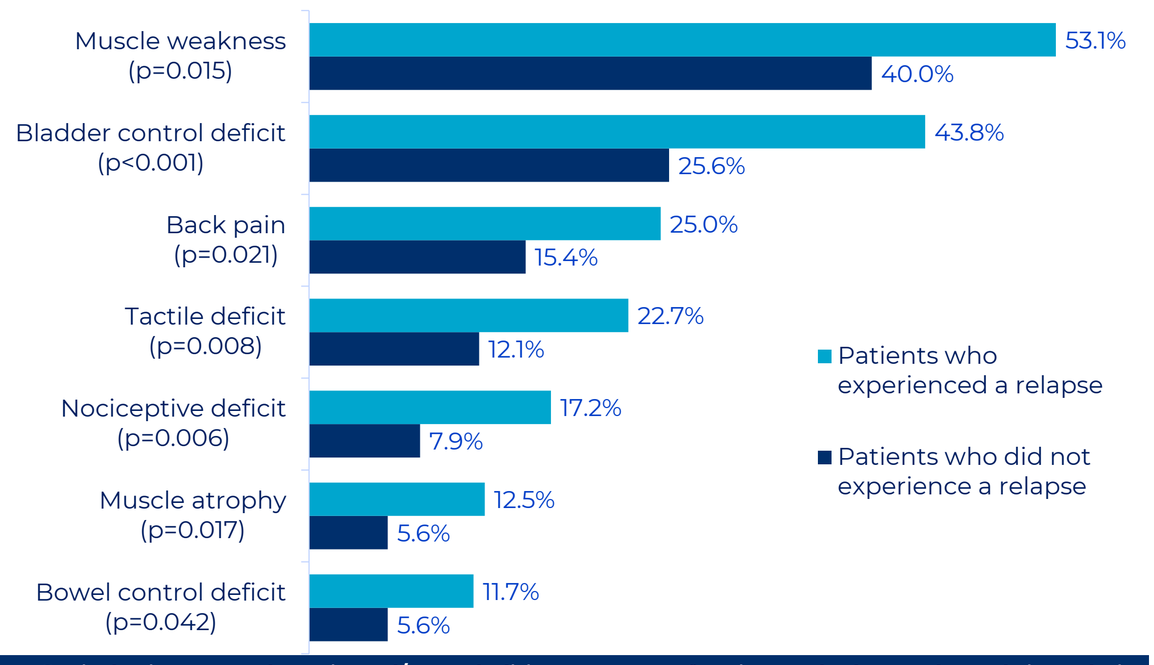


Figure 3. Optic, brainstem and meningeal/encephalitic symptoms of patients who have relapsed since their initial NMOSD attack vs patients who do not have a physician reported relapse.

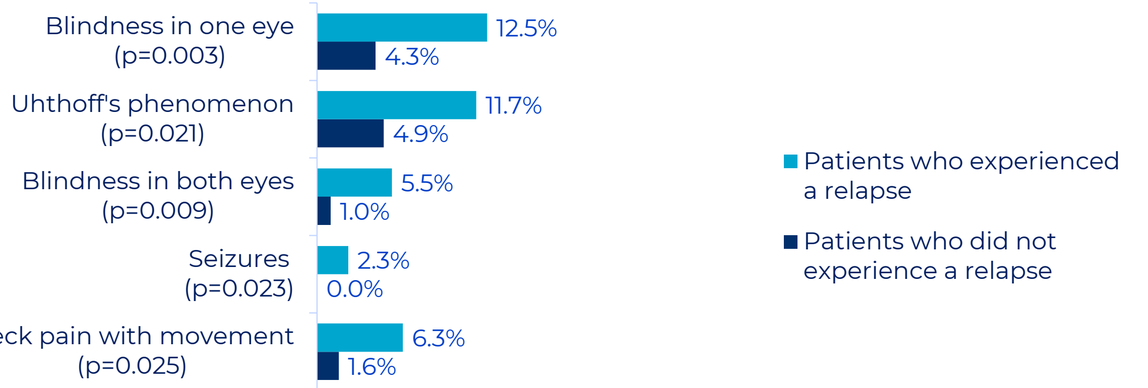
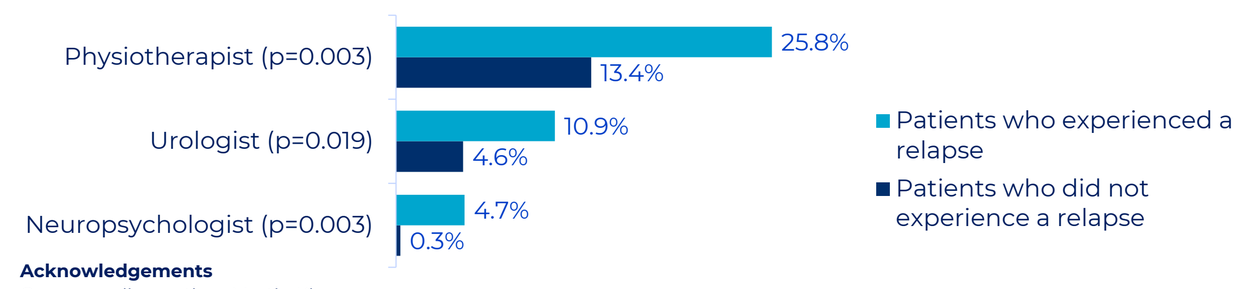


Figure 4. Physicians involved in the management of NMOSD patients who have relapsed since their initial NMOSD attack vs patients who do not have a physician-reported relapse.



CONCLUSIONS

- Patients with NMOSD who experienced a relapse following the initial attack had significantly higher EDSS, experienced more debilitating myelitic symptoms and severe optic impairment compared to patients who did not relapse.
- Patients who experienced a relapse were significantly more likely to consult with a physiotherapist, urologist and a neuropsychologist, highlighting both the physical and psychological impact to the patient.
- These results demonstrate the real-world negative impact of NMOSD relapses on patient outcomes, supporting the importance of disease awareness, accurate early diagnosis and prescription of effective treatment at an early stage of disease, to minimise relapse risk and the associated long-term impact to the patient.

Acknowledgements
Corresponding author: Martin Kleman
The Adelphi NMOSD Disease Specific Programme™ is an independent survey conducted by Adelphi Real World and subscribed to by Alexion. Alexion did not influence the original survey. This analysis was funded by Alexion.

Disclosures
MK, ST, JT and KJM are employees of Alexion Pharma GmbH. MU, GC, ET, NG, LL and KF are employees of Adelphi Real World.

Poster presented at ISPOR 2023

Corresponding author email address: martin.kleman@alexion.com