Patient treatment preferences in myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD)

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Introduction

- MOGAD is a rare, inflammatory demyelinating disease that affects the central nervous system[1]
- Symptoms include vision loss or impairment, weakness and numbness in the limbs, bladder/bowel problems, and cognitive symptoms[1]
- There are currently no approved disease-specific targeted treatments for MOGAD,[2] and untargeted therapy with immunosuppressants and immunomodulators is often used to broadly reduce systemic inflammation and prevent relapse[3–5]
- Understanding patients' experience of MOGAD and their preferences when balancing disease impacts with treatment risks and benefits can both inform therapeutic research and encourage shared decision-making

Methods

- This mixed-methods study combined qualitative semi-structured interviews, a preference elicitation exercise, and a short sociodemographic and clinical questionnaire, which included subsections from two PRO measures (NEI-VFQ-25 and SF-36)
- Patients (aged ≥18 years) with a MOGAD diagnosis from the US, the UK, Germany, or Spain, who self-reported ≥1 relapse (following onset event), were interviewed from January–May 2025
- Interviews were conducted online and included semi-structured discussion of the participant's experience of MOGAD
  - Qualitative data were analyzed using content and narrative analysis techniques
- The quantitative preference elicitation exercise used multi-dimensional thresholding (MDT)[6–8]
  - Six potential treatment attributes were chosen based on the known and anticipated treatment profiles of existing MOGAD treatments and those that may be in development:
    1. Delaying time to relapse
    2. Preventing worsening of vision
    3. Preventing worsening of motor symptoms
    4. Risk of infections
    5. Risk of aseptic meningitis
    6. Risk of headaches
  - A two-step approach was used: 1) participants ranked the attribute scale swings; 2) participants completed single-dimensional thresholding exercises to establish the relative importance of the attributes
  - Preference data were used to estimate each participant's individual attribute weights which express the relative importance of the worst-best improvements
  - Mean weights were used to calculate the maximum acceptable risks for improvements in efficacy

Results

- Demographic and clinical characteristics for the overall population are shown in **Table 1**; PRO subscores are reported in **Table 2**
- Participants reported high impact in many aspects of their lives, including work (n=26/27, 96%), emotions (n=25/27, 93%), and activities of daily life (n=23/27, 85%). The three most commonly reported symptoms, either currently or during a relapse, were vision impairment (n=19/27, 70%); sensory issues with limbs, hands, or feet (n=15/27, 56%); and bladder issues (n=12/27, 44%)
- MDT showed that delaying time to relapse was the most important attribute for participants, followed by preventing worsening of vision and preventing worsening of motor symptoms (**Figure 1**)
  - Participants gave greater weight to treatment benefits than risks; risk attributes had comparatively low importance
- Participants were willing to trade-off accepting additional treatment risks in exchange for additional treatment benefits (**Table 3**)
  - For each additional month in delaying time to relapse, participants were willing to tolerate a 3.4% increase in aseptic meningitis risk, an 8.6% increase in infection risk, or a 28.8% increase in headache risk
- Qualitative quotes also suggest that "longer time to relapse" is perceived as being associated with reduced overall symptom worsening and improved quality of life (**Figure 2**)

Table 1. Demographic and clinical characteristics

Characteristic	Overall (N=27)
Median age, years (Q1, Q3)	36 (28, 54)
Female sex at birth, n (%)	22 (81)
Country of residence, n (%)	
United States	22 (81)
United Kingdom	2 (7)
Germany	2 (7)
Spain	1 (4)
Race, n (%)	
White	17 (74)
Black/African/Caribbean/Black British	1 (4)
Asian or Asian British	3 (11)
Latino or Hispanic	2 (9)
Prefer not to say	1 (4)
Not asked (not US or UK)	3 (11)
MOGAD presentation, n (%)	
Optic neuritis	7 (26)
Transverse myelitis	4 (15)
Encephalitis	1 (4)
Combination of these	15 (56)
Number of relapses experienced following onset event, n (%)	
One relapse	18 (67)
Two or more relapses	9 (33)
Time since last relapse, n (%)	
Within the last week	2 (7)
1–4 weeks ago	2 (7)
1–3 months ago	2 (7)
4–6 months ago	3 (11)
7–12 months ago	0 (0)
1–2 years ago	6 (22)
More than 2 years ago	12 (44)
Current treatments for MOGAD, n (%)	
IV or subcutaneous immunoglobulin	12 (44)
Immunosuppressants (mycophenolate or azathioprine)	5 (19)
IL-6 inhibitors	5 (19)
Longer-term use of oral steroids (4+ weeks)	4 (15)
B-cell depleters	3 (11)
Short-term use of oral steroids (<4 weeks)	1 (4)
IV steroids	1 (4)
Previous treatments for MOGAD, n (%)	
IV steroids	20 (74)
Longer-term use of oral steroids (4+ weeks)	15 (56)
Short-term use of oral steroids (<4 weeks)	13 (48)
B-cell depleters	9 (33)
IV or subcutaneous immunoglobulin	8 (30)
Plasma exchange (or apheresis)	8 (30)
Immunosuppressants (mycophenolate or azathioprine)	4 (15)
IL-6 inhibitors	1 (4)
Other	1 (4)

IL-6, interleukin-6; IV, intravenous; MOGAD, myelin oligodendrocyte glycoprotein antibody-associated disease.

Table 2. PRO data

PRO score	Overall (N=27)
NEI-VFQ-25 subscore: ocular pain*	
Mean (SD)	69.4 (25.8)
Min, max	12.5, 100.0
Median (Q1, Q3)	62.5 (50.0, 100.0)
SF-36 subscale score: physical functioning†	
Mean (SD)	67.4 (30.8)
Min, max	5.0, 100.0
Median (Q1, Q3)	65.0 (45.0, 95.0)

*For this study, only a subset of questions was included, ie, items #1, #2, #4 and #19, focusing on general health, general vision, and ocular pain. Total score can range from 0 (worst) to 100 (best). The subscore for ocular pain was based on items #4 (pain/discomfort eyes) and #19 (pain/discomfort eyes impact); †For this study, only a subset of questions was included, ie, PF3–PF12, focusing on physical functioning. Total score can range from 0 (worst) to 100 (best).
NEI-VFQ-25, National Eye Institute Visual Function Questionnaire-25; PRO, patient-reported outcome; Q, quartile; SD, standard deviation; SF-36, 36-item short form survey.

Figure 1. Participant preference average weights

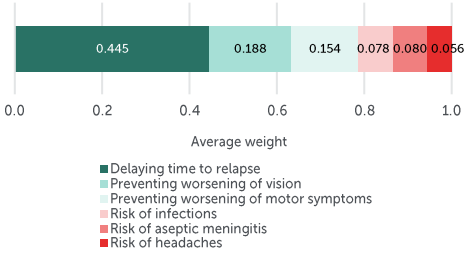

Table 3. Maximum acceptable risks*

	Overall (N=27)
MAR of infections (%)	
Time to relapse (per month)	**8.6**
Worsening of vision (per 10%)	32.4
Worsening of motor symptoms (per 10%)	26.5
MAR of aseptic meningitis (%)	
Time to relapse (per month)	**3.4**
Worsening of vision (per 10%)	13.0
Worsening of motor symptoms (per 10%)	10.6
MAR of headaches (%)	
Time to relapse (per month)	**28.8**
Worsening of vision (per 10%)	>100
Worsening of motor symptoms (per 10%)	89.4

*Population averages with bootstrapped confidence intervals.
MAR, maximum acceptable risk.

Conclusions

This mixed-methods study provides important context to our understanding of **treatment preferences in adult patients with MOGAD**, a disease that substantially impacts many aspects of daily life

Study participants **prioritized the specified treatment benefits** (ie, improved outcomes) over the specified treatment risks, with **delayed time to relapse** considered the most important treatment attribute

Participants were more willing to accept treatment risks when balanced against the possibility of **meaningful extensions in time to relapse** or reductions in the likelihood of certain symptoms (ie, visual and motor impairments)

This study highlights how patients **balance treatment benefits and risks**, providing the aggregate patient perspective to inform benefit-risk assessments. In clinical practice, it is important to consider how **individual and heterogeneous patient experiences** and disease manifestation impact treatment preferences

Figure 2. Participant quotes related to the impact of MOGAD and attribute importance

"I don't think right now anybody thinks we're going to make relapses go away completely. So, **if you can at least extend the time between them, that's a good thing.**"

"If somebody's relapsing every 2 months and then they can go basically almost 2 years between relapses, that's a **quite significant improvement of life.**"

"If I notice that my vision – things like sharpness, etc. is deteriorating, I think that would take away the biggest part of my quality of life… **Vision is everything to me.**"

"To start losing [motor function], **it really felt I was losing actual control of my body.**"

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