

Patient Pathway to Diagnosis of Myelin Oligodendrocyte Glycoprotein Antibody-associated disease (MOGAD): Findings from a Multinational Survey of 204 Patients

Authors: *Jonathan D. Santoro,^{1,2} Jennifer Gould,³ Zoya Panahloo,⁴ Ella Thompson,^{4,5} Julia Lefelar,³ Jacqueline Palace⁶*

Affiliations:

¹Department of Neurology, Keck School of Medicine of USC, Los Angeles, CA, US

²Children's Hospital Los Angeles, Division of Neurology, Los Angeles, CA, US

³The MOG Project, Olney, MD, US

⁴UCB Pharma, Slough, UK

⁵Cogent Skills, Warrington, UK

⁶Nuffield Department of Clinical Neurosciences, University of Oxford, UK

Supplemental Table 1. Categories for analysis of free-text response questions

Question	Categories
Q7: Please explain the reason for waiting more than 1 year to seek medical advice.	Patients sought advice but received an alternative primary diagnosis and/or had problems with getting a diagnosis
	Patients felt that symptoms were not severe or long-term enough to seek medical care
	Patients did not or could not prioritise seeking medical care
	Child was not able to communicate symptoms to parents
Q14: Please explain why it took 7 years or more to get a MOGAD diagnosis from the point of your initial symptoms.	Patients sought advice but received an alternative primary diagnosis and/or had problems with getting a diagnosis
	Patients felt that symptoms were not severe or long-term enough to seek medical care
	Unmet needs and/or lack of awareness among medical community
	Unavailability of MOG-Ig test
	Patients were not believed by healthcare professionals
Q16: Please explain why it took 7 years or more to get a MOGAD diagnosis from	Patients sought advice but received an alternative primary diagnosis and/or had problems with getting a diagnosis
	Patients felt that symptoms were not severe or long-term enough to seek medical care
	Unmet needs and/or lack of awareness among medical community

Question	Categories
the point of when you saw your first doctor.	Unavailability of MOG-Ig test
	Patients were not believed by healthcare professionals
Q22a: Prior to your (or your child's) MOGAD diagnosis, if any, what sort of activities were you unable to perform because of your (or your child's) health problems related to MOGAD?	Perception of overall health and wellbeing (thinking of your overall perception of health and wellbeing in the recent past)
	Activities of a typical day (activities that you would undertake every day or most days such as cooking, cleaning, washing, getting dressed, shopping, driving or travelling to and from your home)
	Accomplishment of work activities (activities that you or your employer would expect you to complete on a scheduled basis as part of your work responsibilities)
	Social activities (willingness or enthusiasm for non-work activities with friends or family)
	Emotional responses (feeling of distress, depression, anxiety, or fearfulness associated with any of the above activities, or a need to cancel activities due to negative emotions)
	Pain (experiencing physical pain in muscles or joints or other parts of the body that have emerged as part of the disease)
	Did not answer question
	No symptoms experienced prior to diagnosis

Question	Categories
Q22b: How did having a final MOGAD diagnosis change anything?	Perception of overall health and wellbeing (thinking of your overall perception of health and wellbeing in the recent past)
	Activities of a typical day (activities that you would undertake every day or most days such as cooking, cleaning, washing, getting dressed, shopping, driving or travelling to and from your home)
	Accomplishment of work activities (activities that you or your employer would expect you to complete on a scheduled basis as part of your work responsibilities)
	Social activities (willingness or enthusiasm for non-work activities with friends or family)
	Emotional responses (feeling of distress, depression, anxiety, or fearfulness associated with any of the above activities, or a need to cancel activities due to negative emotions)
	Pain (experiencing physical pain in muscles or joints or other parts of the body that have emerged as part of the disease)
	Did not answer question
Q23: Have you (or your child) had any long-term health consequences as a	Perception of overall health and wellbeing (thinking of your overall perception of health and wellbeing in the recent past)
	Activities of a typical day (activities that you would undertake every day or most days such as cooking, cleaning, washing, getting dressed, shopping, driving or travelling to and from your home)

Question	Categories
result of not being diagnosed earlier with MOGAD? Please provide details.	Accomplishment of work activities (activities that you or your employer would expect you to complete on a scheduled basis as part of your work responsibilities)
	Social activities (willingness or enthusiasm for non-work activities with friends or family)
	Emotional responses (feeling of distress, depression, anxiety, or fearfulness associated with any of the above activities, or a need to cancel activities due to negative emotions)
	Pain (experiencing physical pain in muscles or joints or other parts of the body that have emerged as part of the disease)
	No long-term health consequences experienced
	Did not answer question

Ig immunoglobulin, *MOG* myelin oligodendrocyte glycoprotein, *MOGAD* myelin oligodendrocyte glycoprotein antibody-associated disease.

Supplemental Table 2. Consultation with doctors during MOGAD diagnostic pathway*

Type of doctor patient was referred to	First doctor consulted about initial MOGAD-related health problems, N=204 n (%)	Next doctor consulted about MOGAD-related health problems, n=200 n (%)	Doctor who made MOGAD diagnosis, n=203 n (%)
Primary care doctor	53 (26.0)	6 (3.0)	0
Paediatrician	14 (6.9)	7 (3.5)	0
Ophthalmologist	31 (15.2)	29 (14.5)	10 (4.9)
Neuro-ophthalmologist	6 (2.9)	29 (14.5)	30 (14.8)
General neurologist	8 (4.0)	56 (28.0)	82 (40.4)
Neuro-immunologist	3 (1.5)	21 (10.5)	61 (30.0)
Movement disorder specialist	0	0	0
Emergency care doctor	79 (38.7)	22 (11.0)	6 (3.0)
Geneticist	0	1 (0.5)	0
Other	10 (4.9)	14 (7.0)	14 (6.9)

NA; not referred to another physician	–	15 (7.5)	–
---------------------------------------	---	----------	---

*Survey Questions 8, 9 and 11.

MOGAD myelin oligodendrocyte glycoprotein antibody-associated disease, *NA* not applicable.

Supplemental Table 3. Time to referral to consultation with a doctor*

Time	Patient population, n=184 n (%)
1 week	126 (68.5)
2–3 weeks	18 (9.8)
4–6 weeks	20 (10.9)
2 months	9 (4.9)
3 months	4 (2.2)
4 months	1 (0.5)
5 months	1 (0.5)
6 months	3 (1.6)
>6 months	2 (1.1)

*Survey Question 10.

Supplemental Table 4. Reasons why it took 7 years or more to receive a MOGAD diagnosis from initial symptoms*

Reasons why it took ≥ 7 years from initial symptoms to MOGAD diagnosis	Patient population, n=29 n (%)
Patients sought advice but faced alternative primary diagnosis and/or problems with getting a diagnosis	14 (48.3)
Patients felt that symptoms were not severe or long-term enough to seek medical advice	4 (13.8)
Unmet needs and/or lack of awareness	7 (24.1)
Unavailability of MOG-Ig test	2 (6.9)
Patients were not believed by healthcare professional	2 (6.9)

*Survey Question 14.

Ig immunoglobulin, *MOG* myelin oligodendrocyte glycoprotein, *MOGAD* myelin oligodendrocyte glycoprotein antibody-associated disease.