Purpose

To conduct an online survey of patients with myelin oligodendrocyte glycoprotein (MOG) antibody-associated disease (MOGAD) and caregivers to explore their perspectives on the experience from onset of first symptoms to final MOGAD diagnosis.

Introduction

MOGAD is a rare, inflammatory, demyelinating condition increasingly recognised as a distinct rare disease.1,2 Low disease awareness and varied access to the MOG antibody test across regions/countries means that early diagnosis of MOGAD can be challenging.

Understanding patients’ and caregivers’ perspectives on symptoms experienced and healthcare interactions leading up to diagnosis is critical to address unmet patient needs in the diagnostic pathway.

Methods

Survey design and administration

Twenty-three multiple-choice and free-text questions were distributed by The MOG Project patient organisation to their patient network via an online survey.

– Scan poster QR code for full survey

– Anonymised responses (collected 18 January to 01 March 2022) were collated using QuestionPro® software

– For simplicity, ‘respondents’ refers to all patients (self- or proxy-reported).

Results

Survey respondent demographics

• Responses were received from 21 countries; 68% of respondents (138/204) were from the United States (Figure 1):
  ∙ MOGAD diagnosis was most often made at <10 years or between 30 to 49 years of age (Figure 2)

Presentation of symptoms

• The most frequently reported first health problem and the MOGAD-related health problem that led respondents to seek medical support were headache (Figure 3) and visual disturbance (Figure 4)

• 81% of respondents (165/204) sought medical advice within 2 months of experiencing symptoms – 8% of patients (16/204) waited >1 year before seeking medical advice.

Pathway from initial consultation to MOGAD diagnosis

• For many patients in the United States (Figure 5) and Europe, Australia and New Zealand (Figure 6), diagnosis occurred following assessment by multiple prior doctors.
  ∙ 24% of respondents (48/204) saw five or more doctors before diagnosis (median=4.0)

• For 18% of respondents (36/204) the time taken from first symptom onset to diagnosis was ≥5 years

• 55% of respondents (113/204) reported receiving an alternative primary diagnosis before final MOGAD diagnosis (Figure 7)
  ∙ The most common primary alternative diagnosis received was multiple sclerosis (33%, 37/113) followed by neuromyelitis optica (12%, 13/113) and acute disseminated encephalomyelitis (9%, 10/113)

• 60% of respondents (123/204) felt they were not given sufficient information and/or resources of the time of diagnosis.

Conclusions

• This survey provides for the first time patients’ and caregivers’ perspectives from the time of first symptoms to final MOGAD diagnosis.

• Approximately 1 in 5 patients reported taking 5 years or more to receive a diagnosis; MOGAD was only recently recognised as a distinct disease, which may account for some delay in diagnosis.

• Approximately 1 to 2 patients reported seeing more than five doctors before receiving a final MOGAD diagnosis. This finding could be in part owing to the lack of awareness of MOGAD among non-specialist healthcare professionals and/or non-availability of diagnostic testing for MOG-Ig at that time.

• There remains a need to understand the regional/country variation in the patient experiences in the pathway to MOGAD diagnosis.

• Greater awareness of MOGAD as a distinct rare demyelinating disease and expert recommendations to support disease definition and diagnosis may help to improve and shorten the pathway from first symptoms to MOGAD diagnosis.

• Further work is needed to assess the impact of earlier diagnosis on the long-term burden of MOGAD and health-related quality of life from the perspective of patients and caregivers.
Thinking back to before you (or your child) were diagnosed by a doctor.

**Pre-survey question:** Which country are you from?

**Patient Survey Questions**

4. Thinking back to before you (or your child) were diagnosed by a doctor.

5. What were the main MOGAD-related health problems occur?†

   As best as you can recall, in what order did these symptoms that required you to seek medical care?

   i. Cold/flu-type symptoms
   j. Other, please specify
   k. Eye pain
   l. Other, please specify
   m. Other pain

3. Thinking back to before you (or your child) were diagnosed with MOGAD, which of the following was the very first health problem you remember experiencing? Select all appropriate responses.

4. Thinking back to before you (or your child) were diagnosed with MOGAD, what other MOGAD-related health problems developed after your first health problem of response to Q3? As best as you can recall, in what order did these other health problems occur? *Drop and drag exercise where respondents select and order from the list below.*

5. What were the main MOGAD-related health problems that eventually made you (or your child) seek medical advice from a healthcare professional? In other words, what were your most severe symptoms that required you to seek medical care? Select all appropriate responses.

6. How long did it take between your first MOGAD symptom and seeking medical advice?

7. If the answer to Question 6 = D. Please explain the reason for waiting more than 2 years to seek medical advice.

8. What type of doctor did you (or your child) see when you first sought medical advice for your initial MOGAD health problems?

9. What type of doctor were you (or your child) referred to next?

10. How long did you (or your child) have to wait to see the doctor to which you were referred?

11. What type of doctor eventually made your (or your child’s) diagnosis of MOGAD?

12. How many different doctors did you (or your child) see in total before you finally received your diagnosis of MOGAD?

13. From the time that you (or your child) first experienced health issues related to MOGAD, how long did it take to get diagnosed with MOGAD?

14. If the answer to Question 13 = 1. Please explain why it took 7 years or more to get a MOGAD diagnosis from the point of your initial symptoms.

15. From the time that you (or your child) saw the very first doctor for your initial health problems, how long did it take to get diagnosed with MOGAD?

16. If the answer to Question 15 = 1. Please explain why it took 7 years or more to get a MOGAD diagnosis from the point of when you saw your first doctor.

17. Thinking back to before you (or your child) had the diagnosis of MOGAD, were you (or your child) misdiagnosed with another illness?

18. Do you feel you (or your child) were provided with enough information and support at the time of your (or your child's) MOGAD diagnosis?

19. If the answer to Question 18 = B. What information and/or resources would you have liked to receive at the time of your MOGAD diagnosis?

20. Which type of doctor do you currently see for the management of your MOGAD?

21. Please share any thoughts you have about your ‘journey’ from first experiencing health issues related to MOGAD, to when you were finally diagnosed with MOGAD. Please include your thoughts about the importance of the value that you give to having a proper and timely diagnosis and how the diagnostic process could be improved.

22. Prior to your (or your child’s) MOGAD diagnosis, in any, what sort of activities were you unable to perform because of your (or your child’s) health problems related to MOGAD? How did having a final MOGAD diagnosis change anything?

23. Have you (or your child) had any long-term health consequences as a result of not being diagnosed earlier with MOGAD? Please provide details.

*Response options were presented in a random order for all multiple-choice questions. Questions 3 and 4 were presented as one question; respondents were asked to select health problems in the order in which they occurred, starting with the first health problem experienced.

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