

SUPPLEMENTARY INFORMATION

Patient experience of myelin oligodendrocyte glycoprotein antibody-associated disease: qualitative patient and clinician interviews informing the development of a conceptual model

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Appendix A1: Targeted literature review – abstract eligibility criteria

The prespecified criteria for abstract inclusion/exclusion in the qualitative review are listed below.

1. Abstracts will be included in the qualitative review if they meet any of the following criteria:
 - Abstract includes reference to the symptoms and/or impact of symptoms experienced by patients with myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD), as reported by patients or their caregivers. Note: inclusion will be extended to include clinician reports should patient-reported information prove limited
 - Abstract includes reference to qualitative design/methodology (e.g. interviews, focus groups, patient reports etc.). Note: inclusion will be extended to include quantitative design methodology (e.g. structured interviews or survey studies) where appropriate; however, caution will be exercised regarding their inclusion as disease/impact concepts of interest are typically pre-specified by the researchers, study design, and/or questionnaire content, unlike interview and focus group methodology where relevant concepts are typically elicited more spontaneously
2. Abstracts will be excluded if they meet any of the following criteria:
 - Abstract is not related to MOGAD symptoms or impacts
 - The main focus of the abstract concerns genetic, biomedical, physiological, and/or epidemiological aspects of MOGAD
 - Abstract concerns healthcare service evaluation in MOGAD
 - The main focus of the abstract does not concern information relevant to the aims of the literature review

Table S1: Overview of the patient experience of symptoms of MOGAD with example quotes from patient interviews

Symptom domain/concept	No. of patients ^a	Example quotes from patient interviews
Constitutional		
Fatigue	12/12	"I always wake up feeling like I haven't slept...even when I am sleeping and I'm in a period where I am sleeping much better, I'm still always exhausted and always tired."
Body aches/pain	11/12	"I mean there's always the shooting pains coming around in my neck, my back, and also my abdomen. Sometimes it's always, you know, shooting...tingling also."
Loss of appetite	4/12	"Sometimes I just lose appetite for weeks...and I'm unable to eat or...I find it very hard to, to take in food."
Fever	3/12	"Sometimes I get real sick and feverish...I'm feeling feverish, yet I'm sweating. I'm real sweaty."
Visual		
Eye pain	12/12	"It's more of a sharp pain. So when you look, it's like a needle in your eye."
Blurred vision	11/12	"I started having disturbing eyesight that when I look at something I could have difficulty identifying what I am actually looking at...this is something...I notice for...a couple of weeks."
Flashes of light or auras	9/12	"Flashes of light, every time I went into a dark room and I would look around at my eye, there'd be bright flashes."
Partial or full blindness	7/12	"My first bilateral optic neuritis attack...it lasted maybe about 14 days until I got my—the first dose of steroids...high doses of steroids. And then I completely got it back, but not fully, after three months."
Loss of color vision	5/12	"Most times I have...color confused. [I] couldn't...identify a specific color."
Double vision	4/12	"I had complete double vision. I saw two of everything with great separation between."
Reduced visual acuity	2/12	"So my acuity in my left eye is now like probably negative eight and my right eye is like two and a half."
Neurological: General		
Headaches	11/11	"It's mostly just throbbing headaches in different locations."
Speech difficulties	9/11	"There were actually a couple of times when I want to speak to someone about something and it's like I just froze and my brain is unable to, to send a signal to my mouth so I could utter the words."
Sensory changes	6/11	"I'm just extremely more sensitive to sound...compared to what I was before I had MOG antibody disease."
Dizziness	4/11	"I do experience a lot of vertigo and dizziness...which then can kind of correspond with some nausea...it feels like motion sickness at times."
Seizure	3/11	"First it started with the confusional migraine and then it went into a slow-motion seizure."
Difficulty swallowing	3/11	"I'll choke on my own spit, aspirate she [clinician] called it."
Neuropsychiatric symptoms	2/11	"I'll be having a conversation just like me and you are right now and I'll just—my mind will go blank and I'll be like, I don't know what I was going to say."

Neurological: Sensory-motor		
Weakness	10/10	"It [weakness] just kind of didn't stop. And so we found that there was distinct weakness in the right side...so there's always present symptoms."
Numbness/tingling	10/10	"Baseline the numbness and tingling is always there...that feeling of...limbs falling asleep."
Balance difficulties	10/10	"I feel unsteady on my feet...and I guess there's some fear with that kind of a day too 'cause I worry about falling."
Partial or full paralysis	3/10	"I woke up and I couldn't move. Couldn't lift my head. Couldn't move my body."
Tremor	3/10	"Shakiness in my hands...my left hand would, uh, shake a bit, quite a bit actually."
Muscle spasms	2/10	"I'll have those random muscle spasms in my legs or in my arms and I can't sleep because my, you know, my body is trying to spasm in whatever different direction for no reason."
Genitourinary		
Urinary symptoms/difficulties	8/8	"The urgency and frequency [to urinate] is kind of just there all the time."
Gastrointestinal		
Bowel symptoms	5/6	"Sometimes I couldn't even control it. Like I could get up to walk across the room and have diarrhea...wake up in the middle of the night with it, have it in my sleep. It was really—it was horrible."
Nausea/vomiting	3/6	"[Nausea] feels like motion sickness at times."
Chest-related, respiratory, and throat		
Chest symptoms	4/4	"I do have these...pains in my chest. And like something was taken out of there and I just need a couple of minutes before I could regain full energy in that part of my body"
Difficulty breathing	3/4	"I do get...a sensation of like somebody is choking me, but there's nothing there."
Throat symptoms	1/4	One patient reported that they experienced throat symptoms, but no further detail was provided.

Patient IDs are not included to maintain anonymity and avoid potential identification of patients from their combination of symptoms, but quotes in this table represent statements from 10 different patients.

^aAll patients did not report each symptom domain (bold). The denominator represents the total number of patients that reported the respective symptom domain.

MOGAD, myelin oligodendrocyte glycoprotein antibody-associated disease.

Table S2: Duration of MOGAD symptoms as reported by patients

Symptom domain/concept	Number of patients reporting duration / total number of patients ^a	Durations reported ^b
Constitutional		
Fatigue	5/12	Constant (<i>n</i> =2) Up to a month (<i>n</i> =1) Up to a week (<i>n</i> =2) Up to a day (<i>n</i> =1)
Body aches/pain	5/11	Constant (<i>n</i> =1) Up to a month (<i>n</i> =2) Up to a day (<i>n</i> =3)
Loss of appetite	2/4	Constant (<i>n</i> =1) Up to a month (<i>n</i> =1)
Fever	0/3	–
Visual		
Eye pain	4/12	Constant (<i>n</i> =2) Short-lived (<i>n</i> =2)
Blurred vision	4/11	A day (<i>n</i> =2) Up to a week (<i>n</i> =1) Up to a month (<i>n</i> =1)
Flashes of light or auras	2/9	Minutes to hours (<i>n</i> =1) Up to a week (<i>n</i> =1)
Partial or full blindness	4/7	Multiple months (<i>n</i> =3) Minutes to hours (<i>n</i> =1) Up to a week (<i>n</i> =1)
Loss of color vision	0/5	–
Double vision	1/4	Up to a month (<i>n</i> =1)
Reduced visual acuity	0/2	–
Neurological: General		
Headaches	4/11	Up to a week (<i>n</i> =2) Minutes to hours (<i>n</i> =1) Up to a month (<i>n</i> =1)
Speech difficulties	1/9	Minutes to hours (<i>n</i> =1)
Sensory changes	0/6	–
Dizziness	1/4	Up to a month (<i>n</i> =1)
Seizure	1/3	Minutes to hours (<i>n</i> =1)
Difficulty swallowing	0/3	–
Neuropsychiatric symptoms	1/2	Up to a week (<i>n</i> =1)
Neurological: Sensory-motor		
Weakness	5/10	Constant (<i>n</i> =5)
Numbness/tingling	4/10	Constant (<i>n</i> =1) Up to a month (<i>n</i> =1) Up to a week (<i>n</i> =1) Minutes to hours (<i>n</i> =1)
Balance difficulties	1/10	Up to a month (<i>n</i> =1)
Partial or full paralysis	0/3	–
Tremor	0/3	–
Muscle spasms	0/3	–

Genitourinary		
Urinary symptoms/difficulties ^c	2/8	Constant (<i>n</i> =1) A day (<i>n</i> =1)
Gastrointestinal		
Bowel symptoms	1/5	Months (<i>n</i> =1)
Nausea/vomiting	0/3	-
Chest-related, respiratory, and throat		
Chest symptoms	1/4	Minutes to hours (<i>n</i> =1)
Difficulty breathing	1/3	Less than a day (<i>n</i> =1)
Throat symptoms	0/1	-

^aNumber of patients who reported duration information / number of patients reporting the symptom. Although questions were asked to obtain additional symptom descriptions as part of the interviews, patients did not always discuss the duration of symptoms. For instance, 0/3 for fever indicates that 3 patients reported fever, but 0 of those patients reported the duration of fever.

^bIn some instances, patients reported more than one duration; as a result the *n* values in this column may exceed the number of patients who reported duration information.

^cDuration varied across symptoms (urinary urgency, frequency, and unspecified)

MOGAD, myelin oligodendrocyte glycoprotein antibody-associated disease.

Table S3: Overview of the patient experience of HRQoL impacts of MOGAD with example quotes from patient interviews

HRQoL impact domain/concept	No. of patients*	Example quotes from patient interviews
Emotional wellbeing		
Depression	10/12	"I do think when you're constantly not feeling well and you're...constantly in pain, constantly tired...how do you stay positive through all that?...I would say I have experienced depression...my mood has been very negatively affected."
Fear	8/12	"It's...a scary thing to feel like...there's no cure. That it's going to progress."
Worry/anxiety	8/12	"Every time a thought would come into my head about what's happening or if I get like a headache...I more or less can't think of anything else other than oh, is this going to be another relapse."
Frustration	5/12	"Being half blind does not help...especially if I like stand up and I'm walking...I'll get dizzy or I'll have to stop and sit down for a second...that's annoying."
Embarrassment	4/12	"I sometimes live like a blind person...I end up, you know, stating the wrong color. Probably I want to reference to a blue color and then I happen to see it's a pink color. It's so embarrassing. It has embarrassed me several ways directly and indirectly."
Heightened emotions/mood swings	3/12	"The smallest, little things would trigger me... I get defensive I guess if...somebody pointed out that I did something wrong or...yelling and screaming sometimes."
Stress	3/12	"I think the bad is a big one because I've developed severe anxiety...and PTSD from having MOGAD and the experiences that have come with the relapses."
Reduced motivation/apathy	3/12	"I mean I want to lie on the couch really and do nothing. Nap or read or something like that, but...usually I have diminished appetite on those days too. So I really have no...urge to get up...it's really debilitating on the days that I have the fatigue."
Overwhelmed	2/12	"The fatigue just feels overwhelming. Like on the days when I have it really bad...I want to lie on the couch really and do nothing. Nap or read or something like that, but...usually I have diminished appetite on those days too."
Distress	2/12	"It seems to me like it distracts me a lot, especially outside in the public. It just makes me go crazy sometimes."
Emotional fatigue	2/12	"I was just mentally and physically fatigued and I was in so much pain and I didn't feel myself...I was oblivious to where I was or what was going on."
Anger	2/12	"So I'll start snapping...normally it's my wife unfortunately. So sometimes it'll be like my friends, like if we're in a grocery store...and I'm getting tired because we've been walking around for a while I'm like okay, I'm done. And I'll start getting snappy like okay, I need to go home."
Stigma	1/12	"A lot of people who doesn't know what I'm going through, the disease I have, might not understand me. They just see me to be a very moody person."
Low self-esteem	1/12	"My beauty has been killed."
Shock	1/12	"Yes." (when asked if they had experienced feelings of shock associated with MOGAD)
Gratitude	1/12	"It's kind of made me a better person. It made me appreciate, you know, things that I have, my vision, my family, people that I love."
Motivation/determination	1/12	"It's made me be...a little bit more determined to get things done."

Activities of daily living		
Difficulty carrying out household chores	11/12	"Standing washing the dishes is very difficult some days...I have a basement. That's where my washer and dryer are...some days using the steps to go up and down is harder than other days."
Difficulty driving	9/12	"Not having any peripheral vision, not being able to drive because I don't have peripheral [vision]...is also difficult."
Difficulty reading	8/12	"Reading is difficult because...like I can't maintain reading certain things for a long period of time because of my vision."
Diet affected	6/12	"I think [the double vision was made worse by] food I was eating... I had a total revamp of my diet."
Difficulty carrying out self-care activities	5/12	"Due to the fatigue, some days...I don't feel like I can get up and take a shower."
Difficulty taking part in hobbies	4/12	"I like to play basketball and the table tennis, but...over the past three to four years now, I have slowly drifted away from my sports activities and all of the communities that I identify with."
Difficulty shopping	2/12	"Going out to the grocery store and seeing different colors and all those kind of stuff and my eyes kind of drawing left and right all the time would definitely trigger a headache."
Difficulty with caregiving responsibilities	2/12	"I still had pain around my eye, so I couldn't really look left or right. I have...two kids...even just like playing around with them, it was a challenge."
Difficulty with screen-based activities	1/12	"I still didn't..., play videogames just 'cause, 'cause it's so bad and it strains your eyes quite a bit."
Physical functioning		
Difficulty walking	10/12	"As of right now I had a transverse myelitis attack in June 2021 and I've been on a cane and/or walker since. I'm finally seeing some...improvement in my mobility and I'm trying to capitalize on that as much as possible."
Difficulty carrying out sport and exercise activities	8/12	"I used to do kickboxing. Can't do that anymore...I tried to do yoga, but because of my balance...I can't do that either."
Difficulty with balance and coordination	5/12	"Every time I walk when I have balance issues, I can't really walk. I tip to one side and end up falling over...it's not really nice kind of state to be in."
Difficulty standing	4/12	"Sometimes when I'm standing, I can't stand for a long time...and so, so I tend not to...if it's around the period where I will be having this...imbalance—the balance problems."
Reduced stamina	2/12	"And so then post the transverse myelitis attack...my daily ability...my stamina...my mobility was quite affected, I lost a lot of muscle."
Weight loss	1/12	"I am not longer a lively person I used to be. I no longer do the things I used to be. I have lost weight. A lot of things happened."
Increased susceptibility to colds and viruses	1/12	"It's an autoimmune so you can catch pretty much everything...I always wondered why I always—you know, if there was a cold, I would catch it. Now I know."
Social functioning		
Impaired relationships with friends/family and/or partner	9/12	"If I'm...having bad days, it's hard to keep up with some of my friends...they want to talk to you every day...sometimes I have days where I don't want to talk to anybody...I'm having brain fog. I'm having a migraine. Don't talk to me. Leave me alone."
Reduced social participation	9/12	"Because of all the symptoms, I really didn't have energy for anything outside of work...since the transverse myelitis attack, I've been very isolated...when you get severely sick to the point where you're not able to reciprocate it...people tend to fall out of the woodwork in my experience. I've definitely become very isolated."
Withdrawing from activities	5/12	"If a friend calls and says, let's go and do whatever, I may not necessarily go where in the past I would have gone."
Reduced independence	3/12	"[Numbness/tingling] makes it very hard for me to perform normal activities. And I need to get people to do stuff for me most times."

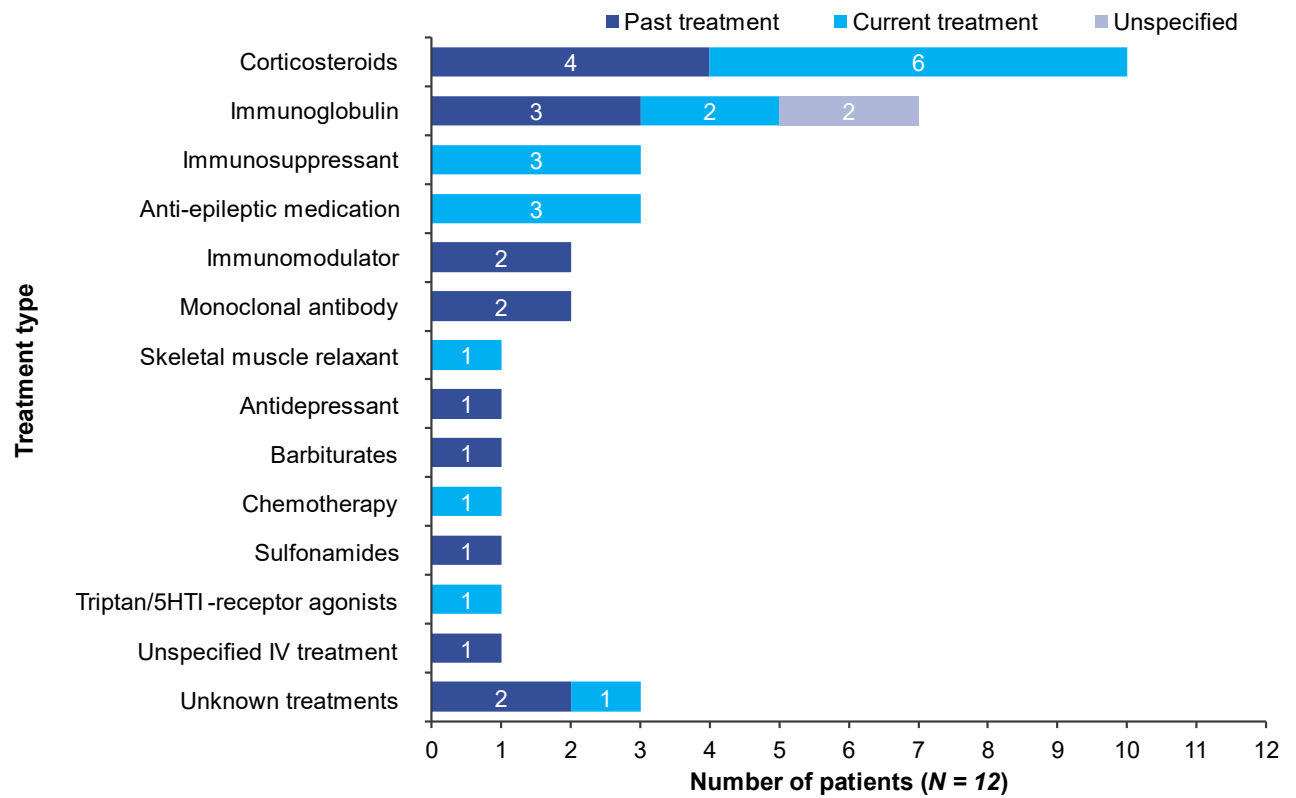
Work/school		
Inability to work	11/11	"You know, I've lost my vision, kind of dropping everything, not being able to go to work...just to go and get those relapses under control."
Advocacy for others	1/11	"If it wasn't for me having MOGAD or honestly being diagnosed...I never would have become...[job title]...and definitely not the one that...looks after those...who have neural developmental and other disorders."
Difficulty completing schoolwork	1/11	"It's very difficult to concentrate whenever your head is throbbing and so I couldn't...it was hard to do my schoolwork."
Cognitive functioning		
Difficulty concentrating	8/11	"Well it's very difficult to concentrate whenever your head is throbbing...it was also hard to keep a conversation...I couldn't concentrate to save my life."
Confusion	7/11	"I had the severe pains in my eyes...since it has to do with my eyes, it sometimes affects...my day-to-day life because whenever I'm going shopping to pick some things, I tend to be confused most times. I am not getting the exact thing I am trying to look for or trying to always mistake some other thing for the exact thing I want."
Memory problems	6/11	"Remembering is hard. I have to sometimes read things two or three times. I have to take...very deliberate note...I keep a calendar in my phone, on my iPad, everywhere just to remember."
Brain fog	2/11	"Brain fog can prevent me from remembering words or remembering things. And then as I'm speaking, I'll forget mid-sentence. That happens quite frequently."
Cognitive fatigue	1/11	"The mental stamina...it was a lot, along with the fatigue I think and the brain fog...and I don't feel like I have the mental stamina or the capacity."
Sleep		
Insomnia	4/10	"Then the eye pains, my god. It was so bad that I couldn't even sleep at night."
Night-time awakenings	4/10	"When I for example have eye pain or a headache, I would probably not sleep or I would wake up around four times or during the night."
Difficulty falling asleep	3/10	"At night...it's gotten better recently because...I take some CBD gummies...seems to really actually help me to fall asleep. Now help me staying asleep is a different story...I'll have a really...bad day of spasms and sleeping will just be a challenge."
Increased sleep	2/10	"Extreme fatigue...I would sleep most of the day. I can sleep 17 hours a day not being able to get out of bed."
Financial		
Financial strain/burden (e.g. cost of treatment)	7/7	"The only person that's working is my wife...it's very difficult to pay rent, do grocery shopping, and stay up to date on my prescriptions...it's hard to have a job, so I don't have [health] insurance."

Patient IDs are not included to maintain anonymity and avoid potential identification of patients from their combination of symptoms, but quotes in this table represent statements from 11 different patients.

^aAll patients did not report each HRQoL domain (bold). The denominator represents the total number of patients that reported the respective HRQoL domain.

CBD, cannabidiol; HRQoL, health-related quality of life; MOGAD, myelin oligodendrocyte glycoprotein antibody-associated disease; PTSD, post-traumatic stress disorder.

Fig. S1: Treatments reported by patients



IV, intravenous.