Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis, they could choose from a set lit of symptoms and could then specify other symptoms not listed. Participants with NMOSD had between two and 12 symptoms, and a median of 7.5 symptoms (IQR = 3.75). The most common symptoms before NMOSD diagnosis were loss of clear vision (n=13, 72.22%), eye pain (n=13, 72.22%), muscle spasms (n=12, 66.67%), and sensory loss (n=12, 66.67%).

Participants were asked a follow up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from one to seven, where one is "Life was very distressing" and seven is "Life was great". The median quality of life for participants with NMOSD was between 1.00 and 2.00, for all of the symptoms listed in the questionnaire, this is in the "Life was very distressing" to "Life was distressing" range

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis. The most common symptom leading to diagnosis was visual problems (n=7, 38.89%). There were five participants (27.78%) who described their symptoms leading them to initially be misdiagnosed with MS.

Symptoms leading to diagnosis: Seeking medical attention

There were 13 participants who described having symptoms and seeking medical attention relatively soon after (72.22%).

Symptoms leading to diagnosis: Diagnostic pathway

When asked how they came to be diagnosed with their condition the most common theme was after being admitted to the emergency department or hospital (n=8, 44.44%).

Symptoms leading to diagnosis: Symptom recall

Most participants described symptoms leading to diagnosis in a clear way (strong recall) (n=17, 94.44%). There were no subgroup variations for this theme.

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with NMOSD or MOG. Participants with NMOSD reported between seven and nine diagnostic tests (median =6.00, IQR = 2.50). The most common tests were blood tests (n=18, 100.00%), MRI of brain, optic nerves, or spinal cord (n=17, 94.44%), and physical examination (n=15, 83.33%).

Time from diagnostic test to diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis. Participants with NMOSD were most commonly diagnosed more than four weeks (including over a year) after diagnostic tests (n=8, 44.45%). There were 10 participants (55.56%) who waited less than two weeks.

Time from symptoms to diagnosis

Participants were asked in the online questionnaire approximately when they first noticed symptoms, and when they were diagnosed. Participants with NMOSD were most commonly diagnosed more than a year after first noticing symptoms (n=6, 33.33%), there were two participants diagnosed between six and 12 months after noticing symptoms (n=2, 11.11%), four participants (22.22%) diagnosed between one and six months after noticing symptoms, and three (16.67%) diagnosed within one month after noticing symptoms.

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis. The majority of participants with NMOSD were diagnosed by a neurologist (n=15, 83.33%). Other healthcare professionals that gave the diagnosis included an emergency doctor (n=1, 5.56%), and ophthalmologist (n=1, 5.56%). Over half of the participants with NMOSD were diagnosed at hospital (n=10, 55.56%). Other participants were diagnosed at the specialist's clinic (n=6, 33.33%), and two participants (11.11%) received their diagnosis over the phone.

Form of condition

In the online questionnaire, participants were asked if they were diagnosed with relapsing or monophasic form. No participants were diagnosed with the monophasic form. There were 12 participants (66.67%) with NMOSD who were diagnosed with the relapsing form, and 7 participants who were not sure (38.89%).

Age at diagnosis

Participants were asked in the online questionnaire how old they were when diagnosed. Most of the participants with NMOSD were diagnosed when they were 40 years or older (n=12, 66.67%), and there were six participants (33.33%) who were diagnosed when they were younger that 40 years.

Number of relapses

Participants were asked in the online questionnaire how many relapses they have had. Participants with NMOSD most commonly had one or two relapses, or three or four relapses (n=6, 33.33%). There were three participants (16.67%) that had more than five relapses, and three participants (16.67%) that had no relapses.

Year of diagnosis

Participants noted in the online questionnaire approximately when they were diagnosed. Participants with NMOSD were most commonly diagnosed during 2016 to 2018 (n=7, 38.89%), there were five participants (27.78%) diagnosed during 2019 to 2020, four participants (22.22%) diagnosed between 2011 and 2015, and two participants (11.11%) diagnosed in 2010 or earlier.

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. There were eight participants (44.44%) that described knowing nothing at diagnosis and this was followed by seven participants (38.89%) who described knowing very little. There were 10 participants (55.56%) who described knowing/not knowing about the condition but no specific reason for the level of knowledge.

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis. The majority of participants with NMOSD had no support at the time of diagnosis (n=13, 72.22%), there were three participants (16.67%) that had enough support, and two participants (11.11%) that had some support, but not enough.

Information at diagnosis

Participants were asked in the online questionnaire how much information they or their family received at diagnosis. Half of participants with NMOSD had some information, but not enough (n=9, 50.00%), there were eight participants (44.44%) had no information, and one participant (5.56%) that had enough information.

Costs at diagnosis

Participants noted in the online questionnaire the amount of out of pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests. For those that could remember how much they spent, a follow up question was asked about the burden the costs at diagnosis. There were five participants with NMOSD that had no out of pocket expenses (27.78%), three participants (16.67%) that had spent more than $1,000, and 10 participants (55.56%) that were not sure of the amount they spent. Of the eight participants that could recall the amount they spent, the burden of costs were significant or very significant for four participants (50.00%), a moderate burden for two participants (25.00%), and slightly or not at all significant for two participants (25.00%).

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did. There were no participants that brought the topic up with their doctor. The majority of participants with NMOSD had never had a conversation about biomarker/genomic/gene testing that might be relevant to treatment, (n=13, 72.22%). There were five participants (27.78%) whose doctor brought up the topic with them.

Experience of genetic tests and biomarkers

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test. There were no participants that paid for their test, and there were no participants that were not interested in having this sort of test. The majority of participants with NMOSD did not have any genetic or biomarker tests but would like to (n=11, 61.11%). There were six participants (33.33%) that had tests and paid out of pocket for it, and one participant (5.56%) that had the test through a clinical trial.

Specific biomarkers or genetic markers

For the final question about biomarkers, participants were asked about specific biomarkers that they had that are relevant to their condition. There were seven participants (38.89%) with NMOSD that were not sure if they had specific biomarkers or genetic markers. Five participants (27.78%) had a family history of auto immune diseases, and two had a family history of NMOSD (11.11%). There were 6 participants (33.33%) that were Aquaporin-4, AQP4-IgG, or NMO-IgG positive, and two (11.11%) that were MOG-IgG positive.

Understanding of prognosis

Participants were asked in the structured interview to describe whether they could describe their current outlook or prognosis. There were five participants (27.78%) who described their prognosis in relation to the long-term permanent effects they have suffered from it.

Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis, they could choose from a set lit of symptoms and could then specify other symptoms not listed (Table 3.1, Figure 3.1).

NMOSD

Participants with NMOSD had between two and 12 symptoms, and a median of 7.5 symptoms (IQR = 3.75).

MOG

Participants with MOG had between three and 10 symptoms, and a median of 8.5 symptoms (IQR=3.75).

NMOSD and MOG

Overall, participants with NMOSD or MOG had between two and 12 symptoms, and a median of 7.5 symptoms (IQR = 3.75).

Table 3.1: Number of symptoms before diagnosis

Number of symptoms before diagnosis	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
No symptoms	0	0.00	0	0	0	0.00
1 to 2	2	11.11	0	0	2	7.69
3 to 4	2	11.11	2	25	4	15.38
5 to 6	3	16.67	0	0	3	11.54
7 to 8	5	27.78	2	25	7	26.92
9 or more	6	33.33	4	50	10	38.46

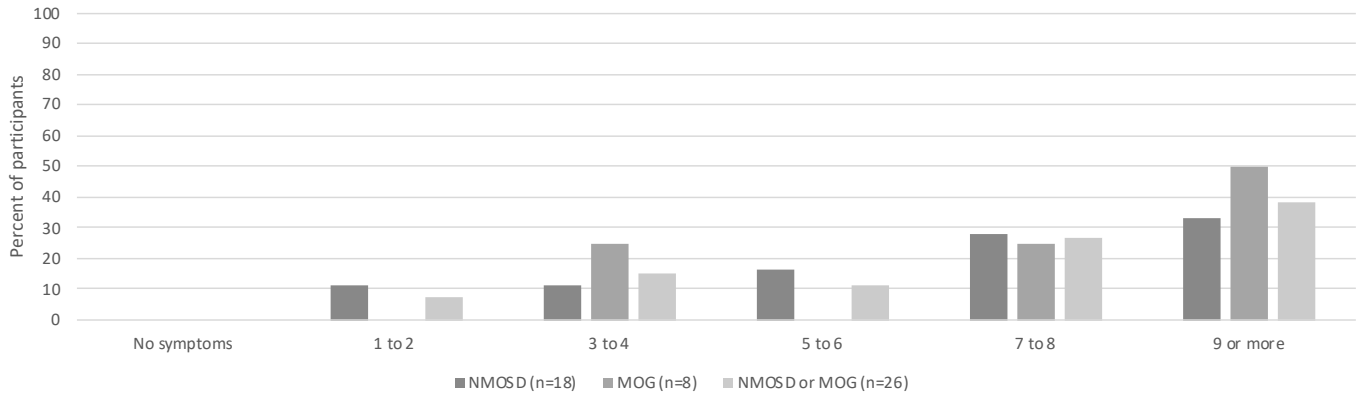

Figure 3.1: Number of symptoms before diagnosis

Symptoms before diagnosis

Participants were asked in the online questionnaire what symptoms they had before diagnosed with either NMOSD or MOG (Table 3.2, Figure 3.2).

NMOSD

The most common symptoms before NMOSD diagnosis were loss of clear vision (n=13, 72.22%), eye pain (n=13, 72.22%), muscle spasms (n=12, 66.67%), and sensory loss (n=12, 66.67%).

MOG

The most common symptoms before MOG diagnosis were loss of clear vision (n=8, 100.00%), inflammation of optic nerve (n=8, 100.00%), eye pain (n=6, 75.00%), and pain in spine or limbs (n=6, 75.00%).

NMOSD or MOG

Overall, the most common symptoms before diagnosis of NMOSD or MOG were loss of clear vision (n=21, 80.77%), inflammation of the optic nerve (n=19, 73.08%), and eye pain (n=19, 73.08%).

Table 3.2: Symptoms before diagnosis

Symptoms before diagnosis	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Inflammation of the optic nerve	11	61.11	8	100.00	19	73.08
Eye pain	13	72.22	6	75.00	19	73.08
Loss of clear vision	13	72.22	8	100.00	21	80.77
Acute myelitis	10	55.56	3	37.50	13	50.00
Pain in spine or limbs	9	50.00	6	75.00	15	57.69
Weakness or paralysis of arms and legs	11	61.11	5	62.50	16	61.54
Loss of bowel or bladder control	11	61.11	1	12.50	12	46.15
Muscle spasms	12	66.67	4	50.00	16	61.54
Sensory loss	12	66.67	3	37.50	15	57.69
Uncontrollable hiccups	3	16.67	1	12.50	4	15.38
Nausea and vomiting	4	22.22	1	12.50	5	19.23
Participants with other symptoms	12	66.67	6	75.00	18	69.23

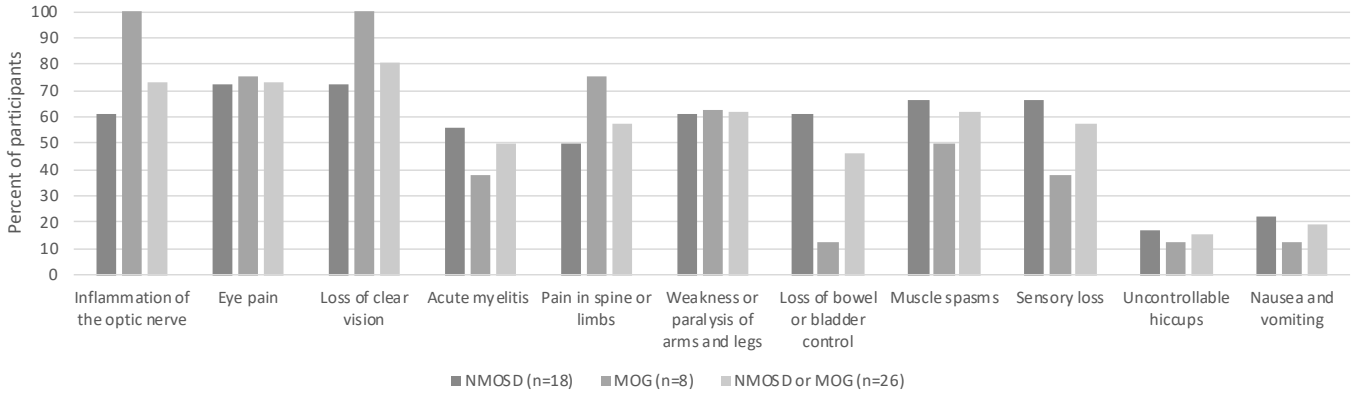

Figure 3.2: Symptoms before diagnosis

Quality of life from symptoms before diagnosis

Participants were asked a follow up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from one to seven, where one is "Life was very distressing" and seven is "Life was great". Where more than five participants experienced the symptom, the median quality of life is displayed in Table 3.3 (Figure 3.3).

NMOSD

The median quality of life for participants with NMOSD was between 1.00 and 2.00, for all of the symptoms listed in the questionnaire, this is in the "Life was very distressing" to "Life was distressing" range

MOG

The median quality of life for participants with MOG from symptoms ranged from 2.00 to 4.00 in the "Life was distressing" to "Life was average" range.

NMOSD or MOG

The median quality of life for participants with NMOSD or MOG was between 1.00 and 2.50, for all of the symptoms listed in the questionnaire, this is in the "Life was very distressing" to "Life was a little distressing" range

Table 3.3: Quality of life from symptoms before diagnosis

Quality of life from symptoms before diagnosis	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Median	IQR	Median	IQR	Median	IQR
Inflammation of the optic nerve	1.00	0.50	2.00	1.25	1.00	1.00
Eye pain	2.00	1.00	4.00	2.00	2.00	2.50
Loss of clear vision	2.00	1.00	2.00	0.00	2.00	1.00
Acute myelitis	1.50	1.75	NA	NA	2.00	2.00
Pain in spine or limbs	1.00	1.00	2.50	1.00	2.00	2.00
Weakness or paralysis of arms and legs	1.00	1.00	2.00	0.00	2.00	1.00
Loss of bowel or bladder control	1.00	1.00	NA	NA	1.50	1.00
Muscle spasms	1.50	2.25	NA	NA	2.50	2.25
Sensory loss	1.00	1.25	NA	NA	2.00	1.50
Uncontrollable hiccups	NA	NA	NA	NA	NA	NA
Nausea and vomiting	NA	NA	NA	NA	2.00	0.00

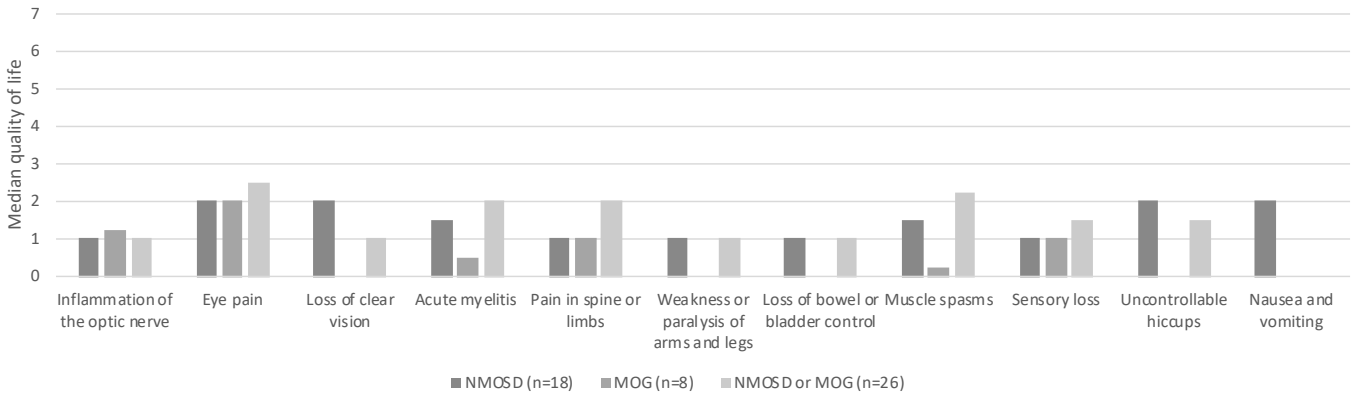

Figure 3.3: Quality of life from symptoms before diagnosis

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis. The most common symptom leading to diagnosis was visual problems (n=7, 38.89%). There were five participants (27.78%) who described their symptoms leading them to initially be misdiagnosed with MS.

Participant describes having visual problems, which led to their diagnosis

The most dramatic thing was on the DATE. We were out the back putting a net over a fruit tree to stop the birds eating our fruit. My wife complained about, she said a dark smudge in her eyesight. That was about ten o'clock in the morning. That progressively got worse and by three o'clock she went to see her GP, who referred her to an ophthalmologist, who she'd seen about four days before for a regular check-up. On that occasion her eyesight was good but this time when she got to the ophthalmologist, she could hardly see, and she was nearly totally blind. Over the period of six or seven hours, she went from a dark smudge to nearly total blindness. From the ophthalmologist who contacted the neuro department at our hospital, we took her up there and she spent the next, I think it was about eight days, in the hospital. She recovered her vision in her right eye, mostly recovered it, I think there's probably a 5% deficit or something like that, but her left eye remained blind. Participant NMOCA_004

Yes. Back in November last year, I was actually trying to recover from whooping cough. I was resting at home, I had a nap in the afternoon and then after I woke up from the nap, the TV was on and when I looked at the TV, it was blurry. Then I tried to get up from my couch and then I started to lose balance. I didn't know what it was. I went to hospital. I just assumed that my whooping cough got worse and that's how it all started. Participant NMO_001

I woke up and had lost my eyesight and before that I didn't even have a headache or anything, so even the night before, I didn't have…I was working, it was over Easter. I didn't have any symptoms at all and woke up and lost half my vision, the upper field of my- at that time it was my right eye. Participant NMO_017

Participant describes their symptoms leading to them initially being misdiagnosed with another condition: MS

Yes. I was actually diagnosed with multiple sclerosis for two and a half years or three years before I got my NMO diagnosis. Before, I was diagnosed with MS, I had numbness in my arm and on the back of my neck, lots of fatigue, and a lot of weakness that would come and go. NMO_003

I went and had an MRI and it showed some lesions in my brainstem and my spinal cord and I was referred to a neurologist. I was first admitted to a hospital and diagnosed with MS. It was about six months later when I was diagnosed with NMO. Participant NMO_010

I was having symptoms and one of the doctors down in LOCATION METROPOLTIAN had diagnosed me with MS. What happened is, I was treated for MS. I had lesions on my spine C2 and C6 and what happened then, he referred me to a neurologist that said it was not NMO. Participant NMO_013

Participant describes their symptoms leading to them initially being misdiagnosed with another condition (general)

He went to see the GP because he just needed to know what was wrong because he felt that something was wrong with his left arm, I think it was. The GP thought that it might be carpal tunnel syndrome. We didn't worry about that too much, but then it just continued. It went for about three months, and then my husband was not…It was going to go away. Participant NMOCA_003

I was like, "Something's wrong with my vision. My head's hurting. Something's wrong." He looked at me and he's like, "Well, you've got an ear infection." I said, "But you're not listening to me. My vision is going." He's like, "Yes. All the nerves in your brain are connected to your ears and that's what's happening to your vision. Take antibiotics." Participant MOG_006

To be honest, I had no idea what tests got ordered when I was there. I just went to ER, they just kept me there. They just did a whole bunch of blood tests. I don't know what they were. Then, I don't know, a day later they told me some sort of brain infection- could be some sort of brain infection going on. A doctor came in to do a lumbar puncture and I still didn't know what was going on. I just thought it was just a brain infection. What kind of infection could be due to the virus? Participant NMO_001

Participant describes having eye pain, which led to their diagnosis

I started to get sore eyes and I thought it must have been windy or something the day before and then it just got worse so I went off to see the eye doctor and they referred me on to a specialist. Participant NMO_007

Yes. So I guess back when I was 13 the first signs were pain behind the eye especially when the eye would move from left to right or up and down. I guess because I was so young I didn't test myself whether I could see out of that eye or not. It wasn't until a few weeks in that I decided that I better go to the doctor. It was really that eye pain for me because although I only really have the optic neuritis components there may have been some transverse myelitis in there as per MRI scans but I wasn't aware of that at the time. Those are the symptoms, eye pain. Participant NMO_002

The symptom for that stage was still weakness in especially my lower limbs, but I would also become weak all over and the eye pain, the temporal pain would come and go. Participant NMO_004

Participant describes having numbness/ paraesthesia, which led to their diagnosis

Oh, sorry. After my arm first went then my whole left side, so my face and left leg went numb, but I still had full mobility and everything else. Participant NMO_014

I had pins and needles in one of my hands and I had some nerve conduction tests carried out. Thinking that it was..I had worked in an office and typed a lot so I was thinking it was like an RSI sort of issue. Looking back now they never found anything on the RSI side of things. Looking back now I sort of say, "Oh, yes. That was an early sign of the MOG." Participant MOG_008

I was totally healthy. It came on in well-- I woke up about three in the morning and I couldn't feel my right-hand side. Participant NMO_009

Participant describes having fatigue, which led to their diagnosis

Yes. That was in about November of 2014 and, I guess, I had no energy because I'm like a ball of energy. I didn't feel sick. I wasn't nauseated. There was nothing. I wasn't hungry, I just felt like I was listless without feeling listless. Then, that was for about, I don't know, a week and I ended up having to go away for a couple of days for work and when I was away, I felt a bit worse and when I got home the doctor came round and gave me some medication, because he thought I had some other condition and I ended up feeling very nauseated and sick. Participant NMO_015

Six months prior to my diagnosis, I just noticed I was getting a lot more fatigued than usual. I used to do quite a lot of walking uphill and downhill and I noticed that that was getting harder and harder. I noticed that my left leg was just not keeping up like it used to. Then about three months before I was diagnosed, I noticed that my vision would just go blurry for no reason. I just noticed that I was just having trouble concentrating when I was reading and also doing my work and computer work, I just was finding it a lot more tiring than usual. MOG_005

Table 3.4: Symptoms leading to diagnosis

Symptoms leading to diagnosis	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes having visual problems, which led to their diagnosis	7	38.89	3	33.33	4	44.44	5	62.50	2	20.00	5	55.56	2	22.22
Participant describes their symptoms leading to them initially being misdiagnosed with another condition: MS	5	27.78	3	33.33	2	22.22	3	37.50	2	20.00	2	22.22	3	33.33
Participant describes their symptoms leading to them initially being misdiagnosed with another condition (general)	3	16.67	1	11.11	2	22.22	1	12.50	2	20.00	2	22.22	1	11.11
Participant describes having eye pain, which led to their diagnosis	3	16.67	1	11.11	2	22.22	2	25.00	1	10.00	2	22.22	1	11.11
Participant describes having numbness/paresthesia, which led to their diagnosis	3	16.67	2	22.22	1	11.11	1	12.50	2	20.00	1	11.11	2	22.22
Participant describes having fatigue, which led to their diagnosis	2	11.11	1	11.11	1	11.11	0	0.00	2	20.00	0	0.00	2	22.22

Symptoms leading to diagnosis	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes having visual problems, which led to their diagnosis	7	38.89	3	30.00	4	50.00	2	33.33	5	41.67	4	57.14	3	27.27
Participant describes their symptoms leading to them initially being misdiagnosed with another condition: MS	5	27.78	2	20.00	3	37.50	0	0.00	5	41.67	3	42.86	2	18.18
Participant describes their symptoms leading to them initially being misdiagnosed with another condition (general)	3	16.67	2	20.00	1	12.50	1	16.67	2	16.67	2	28.57	1	9.09
Participant describes having eye pain, which led to their diagnosis	3	16.67	1	10.00	2	25.00	0	0.00	3	25.00	1	14.29	2	18.18
Participant describes having numbness/parathesia, which led to their diagnosis	3	16.67	3	30.00	0	0.00	2	33.33	1	8.33	1	14.29	2	18.18
Participant describes having fatigue, which led to their diagnosis	2	11.11	1	10.00	1	12.50	1	16.67	1	8.33	1	14.29	1	9.09

Symptoms leading to diagnosis	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes having visual problems, which led to their diagnosis	7	38.89	6	75.00	13	50.00	4	40.00	7	43.75	0	0.00	1	33.33	6	40.00
Participant describes their symptoms leading to them initially being misdiagnosed with another condition: MS	5	27.78	1	12.50	6	23.08	0	0.00	5	31.25	0	0.00	0	0.00	5	33.33
Participant describes their symptoms leading to them initially being misdiagnosed with another condition (general)	3	16.67	2	25.00	5	19.23	5	50.00	3	18.75	0	0.00	0	0.00	3	20.00
Participant describes having eye pain, which led to their diagnosis	3	16.67	1	12.50	4	15.38	1	10.00	2	12.50	1	50.00	0	0.00	3	20.00
Participant describes having numbness/paresthesia, which led to their diagnosis	3	16.67	2	25.00	5	19.23	0	0.00	2	12.50	1	50.00	1	33.33	2	13.33
Participant describes having fatigue, which led to their diagnosis	2	11.11	3	37.50	5	19.23	0	0.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 3.5: Symptoms leading to diagnosis (Subgroup variations)

Symptoms leading to diagnosis	More frequent	Less frequent
Participant describes having visual problems, which led to their diagnosis	Low to moderate fear Moderate to very poor physical function University Aged 18 to 44	High to very high fear Good to very good physical function Aged 45 or older
Participant describes their symptoms leading to them initially being misdiagnosed with another condition: MS	Higher socioeconomic status Aged 18 to 44	Mid to low socioeconomic status

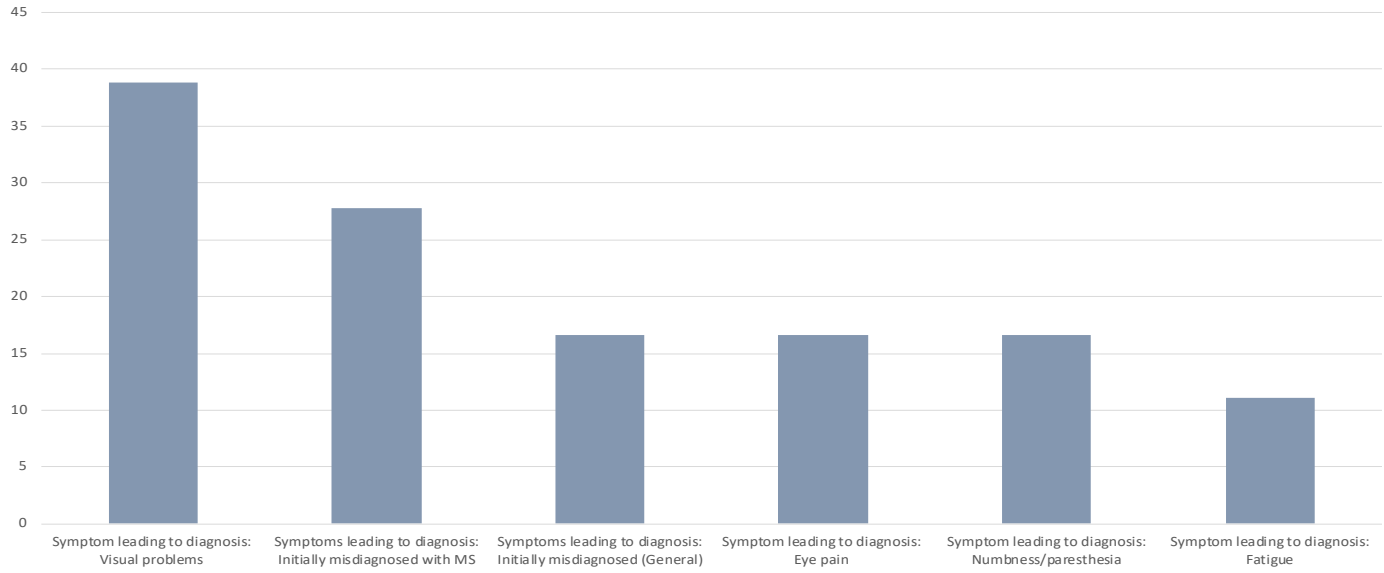

Figure 3.4: Symptoms leading to diagnosis

Symptoms leading to diagnosis: Seeking medical attention

There were 13 participants who described having symptoms and seeking medical attention relatively soon after (72.22%).

Participant describes having symptoms and seeking medical attention relatively soon

Yes. Back in November last year, I was actually trying to recover from whooping cough. I was resting at home, I had a nap in the afternoon and then after I woke up from the nap, the TV was on and when I looked at the TV, it was blurry. Then I tried to get up from my couch and then I started to lose balance. I didn't know what it was. I went to hospital. I just assumed that my whooping cough got worse and that's how it all started. Participant NMO_001

I noticed that I was losing my side vision. It was all black but I had my central vision. It was both my eyes so simultaneous and it was my side vision. I went to the doctor. I had a migraine and it was not going away. I went to the doctor because I had this migraine for 10 days. Participant MOG_006

The most dramatic thing was on the 4th of December 2018. We were out the back putting a net over a fruit tree to stop the birds eating our fruit. My wife complained about, she said a dark smudge in her eyesight. That was about ten o'clock in the morning. That progressively got worse and by three o'clock she went to see her GP, who referred her to an ophthalmologist, who she'd seen about four days before for a regular check-up. On that occasion her eyesight was good but this time when she got to the ophthalmologist, she could hardly see, and she was nearly totally blind. Participant NMOCA_004

Table 3.6: Seeking medical attention

Seeking medical attention	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very goo physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes having symptoms and seeking medical attention relatively soon	13	72.22	8	88.89	5	55.56	7	87.50	6	60.00	5	55.56	8	88.89

Seeking medical attention	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes having symptoms and seeking medical attention relatively soon	13	72.22	6	60.00	7	87.50	3	50.00	10	83.33	5	71.43	8	72.73

Seeking medical attention	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes having symptoms and seeking medical attention relatively soon	13	72.22	5	62.50	18	69.23	7	70.00	11	68.75	2	100.00	1	33.33	12	80.00

Table 3.7: Seeking medical attention (Subgroup variations)

Seeking medical attention	More frequent	Less frequent
Participant describes having symptoms and seeking medical attention relatively soon	Fewer relapses Low to moderate fear Good to very good physical function University Higher socioeconomic status	More relapses High to very high fear Moderate to very poor physical function Trade or high school Mid to low socioeconomic status

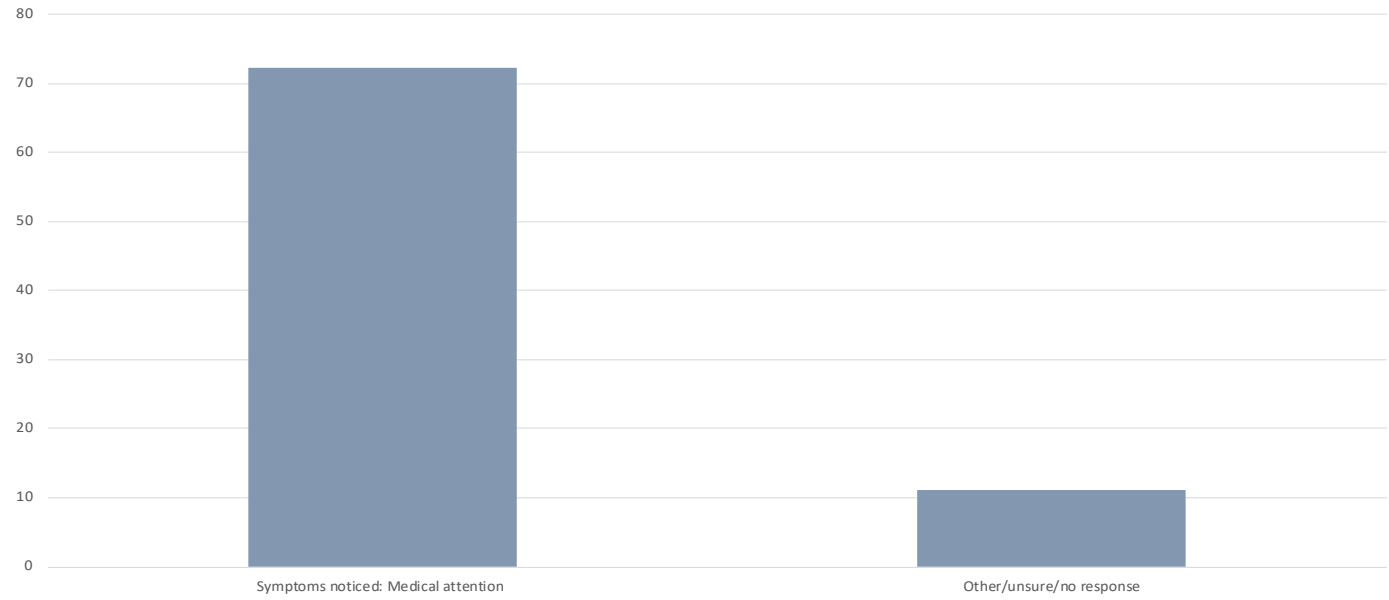

Figure 3.5: Seeking medical attention

Symptoms leading to diagnosis: Diagnostic pathway

When asked how they came to be diagnosed with their condition the most common theme was after being admitted to the emergency department or hospital (n=8, 44.44%).

Participant describes being diagnosed after being admitted into the emergency department or hospital

From that I went into the emergency department and obviously they did an examination and I went into- our hospital has an eye clinic so they were able to have a look behind my eye, et cetera. Saw an eye specialist, a ophthalmo…that's what she's called I think. She was able to see behind the pressure in the eye and from that department I then went to have an MRI. We had, at the time, my family history was my mother had MS, so I think that helped my diagnosis, so straight away I was sent off for bloods. Participant NMO_017

Yes. When we got to NAME HOSPITAL, she was admitted and then we were in emergency for a while. We had an eye doctor come and see us. She said to us if her vision is blurry, it's maybe because she's not well and there isn't anything wrong with her vision. At this time, NAME PERSON CARED FOR said that she could not see anything... He walked out and the neurologist just came running to me out of breath. She said to me, "You need to come with me." Then, she takes me in that little room. She showed me the MRI. She said, "If NAME PERSON CARED FOR can't see, this is why. She has inflammation on her optic nerve." Then, they told me it's NMO. Participant NMOCA_006

I was getting really sick, said to my daughter, nine years ago, "There is something wrong with me, take me to the hospital." I couldn't move the whole thing of-- Just know there was something going on and they opened me up. On the Monday, I could not move from my neck down, I was in hospital for 12 months. Participant NMO_013

Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis

So that was a long winded prognosis. In 2010, I got a test for the blood test for NMO spectrum disorder and that was ordered by a neurologist. Participant NMO_002

He did some tests, and I had, I think, it was hyperreflexia in my left side, so my reactions were a little bit quicker and very jerky. He basically told me he thought I had MS, cancer, or a tumour. He sent me to a specialist, a neurologist, NAME DOCTOR at NAME HOSPITAL. Participant NMO_003

Last August into early September I had gone to see an ophthalmologist neurologist because I had lost the sight in my right eye and that was the third time this had happened to me over the past few years. I was aware that it was optic neuritis but it is was the worst case I've had of it so I got in to see this specialist and he was amazing. He said, "Well,

because you've had something previously I think we should send you for a blood test for something called NMO which is not brilliant but quite often people that have recurring optic neuritis may have this." Because I'd had brain scans and they always showed nothing and he also sent me for a spinal MRI which I'd never had before and within a week or less than a week he rang- maybe a week- he rang me and said he had the blood test results back and I was aquaporin-4 positive for NMO. Participant NMO_006

Participant describes being referred directly to a specialist from their general practitioner but did not initially lead to their diagnosis: multiple specialists needed before diagnosis

I went to my optometrist and he thought I was a retinal detachment because I could see flashing of lights. He sent me to a retina specialist and he's like, "You don't have a retinal detachment. You have optic neuritis." He sent me to the hospital and they did an MRI. I had a mild enhancement, but they kept saying it's optic neuritis. "No. It's not. We need to order CSF." "No. We don't. We need to take serum." "No. We don't." Then, after two days, they were like, "All right. We're just going to let you go. We know something's wrong with you but we don't know what it is so we're not going to treat you and just see how it goes." Three weeks later, my vision is getting worse. I went to my GP and I was like, "Something's not right." He sent me to another specialist who sent me to another hospital and they ordered MOG tests and NMO because I had to last in the hospital. Participant MOG_006

Okay. First, I went to my GP, and he realised that I couldn't see anything, so he sent me to the eye and ear hospital. There, I'm pretty sure they got me in contact-- The first specialist that came to see me was a neurologist, and they sent me for an MRI, I had a field test. I also did a test where-- I'm pretty sure I did a-- I can't remember what it's called, where they take a photo of the eye to see the optic nerve, I'm pretty sure, and that's when it came up that I had lesions behind my eyes. After we got those results, they got me in contact with neurology, and I think it's the MS team with the neuro-ophthalmology-- I think it's like one whole unit at NAME HOSPITAL, then they sent me for a lumbar puncture. Participant NMO_005

He went to see the GP because he just needed to know what was wrong because he felt that something was wrong with his left arm, I think it was. The GP thought that it might be carpal tunnel syndrome. We didn't worry about that too much, but then it just continued. It went for about three months, and then my husband was not-- It was going to go away. He went back to the GP, and luckily he had the foresight of referring him to a neurologist in LOCATION METROPOLITAN. We went to see NAME DOCTOR in the NAME CLINIC. After all the tests that he did, he said, "Look, it is definitely not carpal tunnel syndrome. It is MS." He didn't say anything about MOG. He tried to find a neurologist here in LOCATION METROPOLITAN. That was in April when we went to see NAME DOCTOR. In September the same year, so 2019, we went to see a neurologist here in LOCATION METROPOLITAN, NAME DOCTOR, and he's been treating NAME PERSON CARED FOR ever since. After the first test, he had to undergo a whole-body MRI, couple of blood tests, and I think that was it. Then NAME DOCTOR said that he had spoken with a colleague of his, and they thought that it is more likely to be MOG, rather than pure MS. Participant NMOCA_003

Table 3.8: Symptoms leading to diagnosis: Diagnostic pathway

Path to diagnosis	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very goo physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes being diagnosed after being admitted into the emergency department or hospital	8	44.44	5	55.56	3	33.33	4	50.00	4	40.00	6	66.67	2	22.22
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	4	22.22	1	11.11	3	33.33	2	25.00	2	20.00	2	22.22	2	22.22
Participant describes being referred directly to a specialist from their general practitioner but did not initially lead to their diagnosis: multiple specialists needed before diagnosis	3	16.67	1	11.11	2	22.22	1	12.50	2	20.00	0	0.00	3	33.33

Path to diagnosis	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes being diagnosed after being admitted into the emergency department or hospital	8	44.44	6	60.00	2	25.00	4	66.67	4	33.33	2	28.57	6	54.55
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	4	22.22	2	20.00	2	25.00	0	0.00	4	33.33	3	42.86	1	9.09
Participant describes being referred directly to a specialist from their general practitioner but did not initially lead to their diagnosis: multiple specialists needed before diagnosis	3	16.67	1	10.00	2	25.00	1	16.67	2	16.67	1	14.29	2	18.18

Path to diagnosis	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes being diagnosed after being admitted into the emergency department or hospital	8	44.44	5	62.50	13	50.00	8	80.00	6	37.50	2	100.00	2	66.67	6	40.00
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	4	22.22	1	12.50	5	19.23	0	0.00	4	25.00	0	0.00	0	0.00	4	26.67
Participant describes being referred directly to a specialist from their general practitioner but did not initially lead to their diagnosis: multiple specialists needed before diagnosis	3	16.67	2	25.00	5	19.23	1	10.00	3	18.75	0	0.00	0	0.00	3	20.00

Table 3.9: Symptoms leading to diagnosis: Diagnostic pathway (Subgroup variations)

Path to diagnosis	More frequent	Less frequent
Participant describes being diagnosed after being admitted into the emergency department or hospital	Fewer relapses Moderate to very poor physical function Trade or high school Mid to low socioeconomic status Aged 45 or older	More relapses Good to very good physical function University Higher socioeconomic status Aged 18 to 44

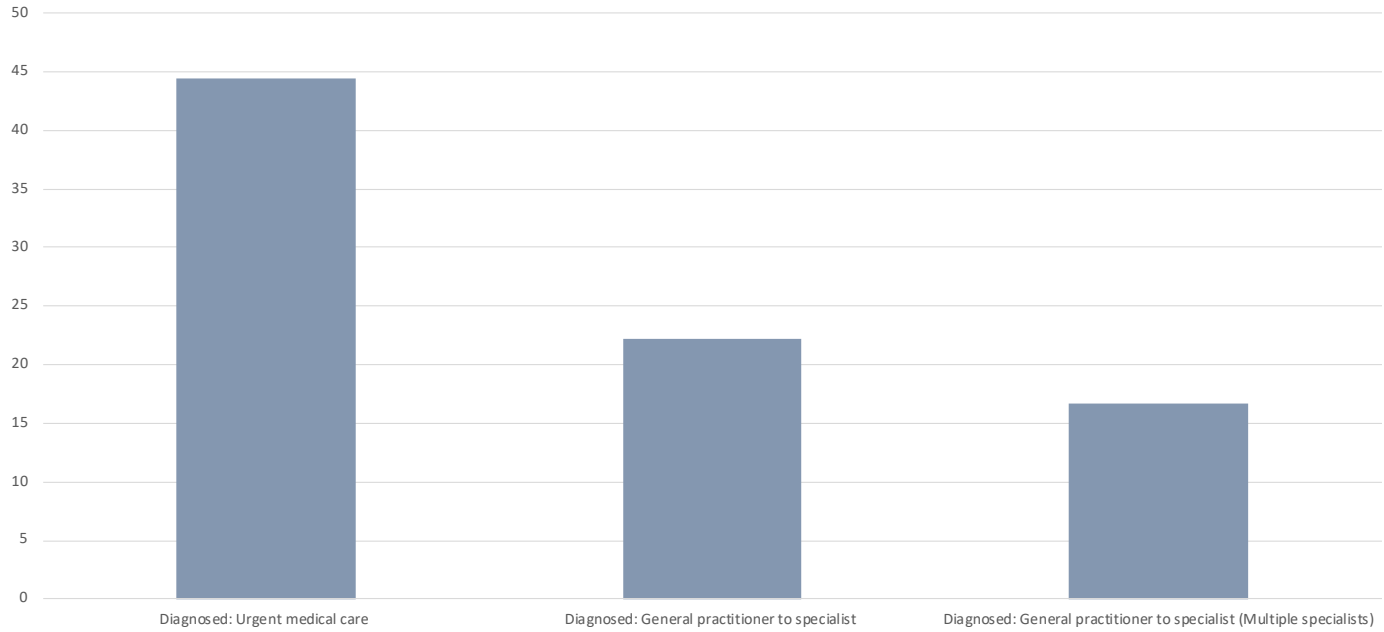

Figure 3.6: Symptoms leading to diagnosis: Diagnostic pathway

Symptoms leading to diagnosis: Symptom recall

Most participants described symptoms leading to diagnosis in a clear way (strong recall) (n=17, 94.44%). There were no subgroup variations for this theme.

Participant describes symptoms leading to diagnosis in a clear way (strong recall)

I woke up about three in the morning and I couldn't feel my right-hand side. It was just all of the sudden. I had no pre-symptoms at all. Participant NMO_009

It's definitely hindsight. I kept getting sick. Things kept happening and I wasn't healing properly. I was tired all the time. I kept having accidents. I kept feeling weak, dropping things. I didn't really know what it was, but then I had a total knee replacement and it didn't heal very well. I had to go back into surgery and have it-- where all the muscles and everything had healed, and then I had to have it-- I can't remember the name of it, but where they stretch it all back again. This thing I did, but if I got a cut, I wouldn't heal, just lots of little things happening. Participant NMO_011

Yes. My first issues were with my eyes, where I had pain when I moved my eyeballs. I had this for about a week or two, like on and off, and I would always joke that maybe I rolled my eyes too much, because it was hurting so much and I just thought I strained a muscle or something. Then it just started to get more and more painful, and then on one eye, I started to get very blurred vision. I went to bed, I woke up, and I didn't see anything. Participant NMO_005

Table 3.10: Symptoms leading to diagnosis: Symptom recall

Symptom recall	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	17	94.44	8	88.89	9	100.00	8	100.00	9	90.00	8	88.89	9	100.0

Symptom recall	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	17	94.44	10	100.00	7	87.50	6	100.00	11	91.67	7	100.00	10	90.91

Symptom recall	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	17	94.44	8	100.00	25	96.15	9	90.00	15	93.75	2	100.00	3	100.00	14	93.33

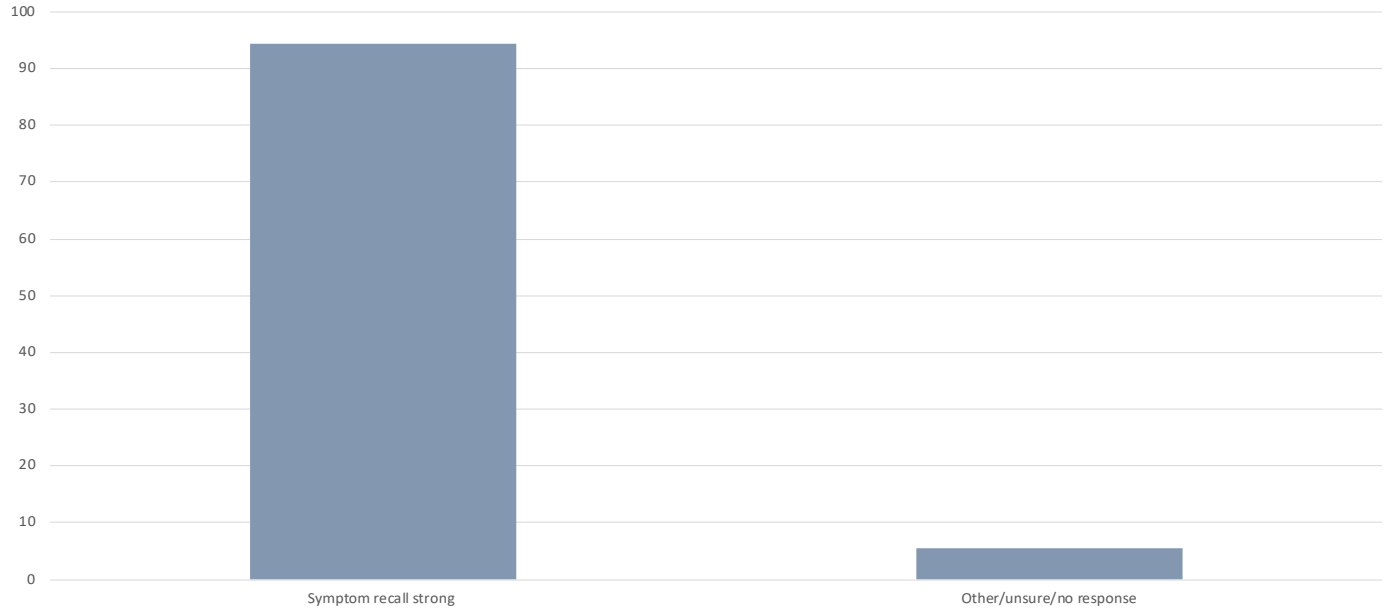

Figure 3.7: Symptoms leading to diagnosis: Symptom recall

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with NMOSD or MOG. They could choose from a set list of diagnostic tests, and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified (Tables 3.11 and 3.12, Figures 3.8 and 3.9).

NMOSD

Participants with NMOSD reported between seven and nine diagnostic tests (median =6.00, IQR = 2.50). The most common tests were blood tests (n=18, 100.00%), MRI of brain, optic nerves, or spinal cord (n=17, 94.44%), and physical examination (n=15, 83.33%).

MOG

Participants with MOG reported between six and nine diagnostic tests (median =7.50, IQR = 1.00). All participants with MOG had blood tests, neurologic exams, MRI or brain, optic nerves or spinal cord, and ophthalmology studies.

NMOSD or MOG

Overall, participants with NMOSD or MOG had between six and nine diagnostic tests (median=7.00,

IQR=2.00). All participants had a blood test (n=26, 100.00%), the other most common diagnostic tests were MRI of brain, optic nerves, or spinal cord (n=25, 96.15%), physical examination (n=22, 84.62%), neurologic exam (n=22, 84.62%), and ophthalmology studies (n=22, 84.62%)

Table 3.11: Number of diagnostic tests

Number of diagnostic tests	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
3 to 4	3	16.67	0	0.00	3	11.54
5 to 6	7	38.89	1	12.50	8	30.77
7 to 8	7	38.89	6	75.00	13	50.00
9 to 10	1	5.56	1	12.50	2	7.69

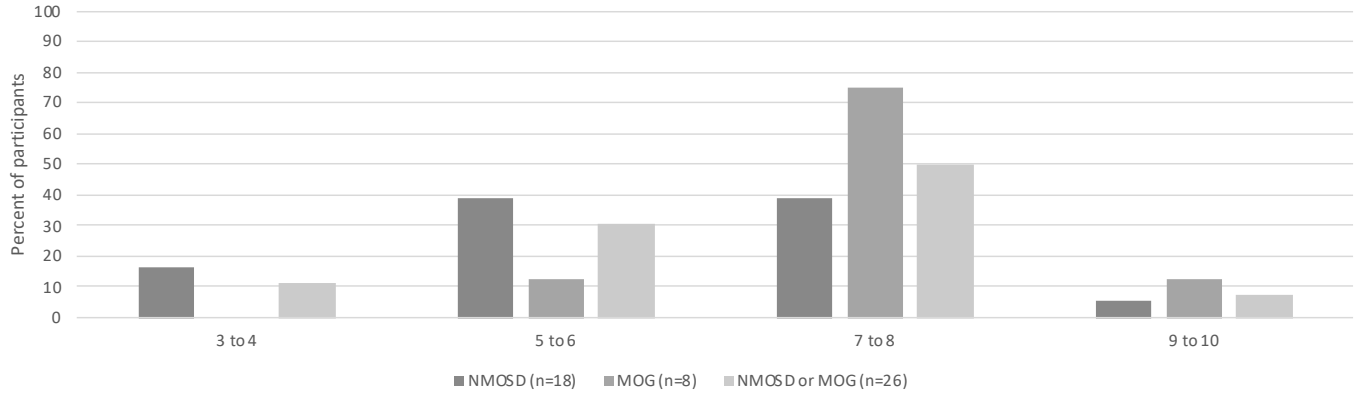

Figure 3.8: Number of diagnostic tests

Table 3.12: Diagnostic tests

Diagnostic tests	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Medical history	13	72.22	7	87.50	20	76.92
Physical examination	15	83.33	7	87.50	22	84.62
Family history	5	27.78	6	75.00	11	42.31
Blood tests	18	100.00	8	100.00	26	100.00
Neurologic exam	14	77.78	8	100.00	22	84.62
MRI of brain, optic nerves, or spinal cord	17	94.44	8	100.00	25	96.15
CT scans	3	16.67	3	37.50	6	23.08
Lumbar puncture	13	72.22	4	50.00	17	65.38
Ophthalmology studies	14	77.78	8	100.00	22	84.62
Other	1	5.56	1	12.50	2	7.69

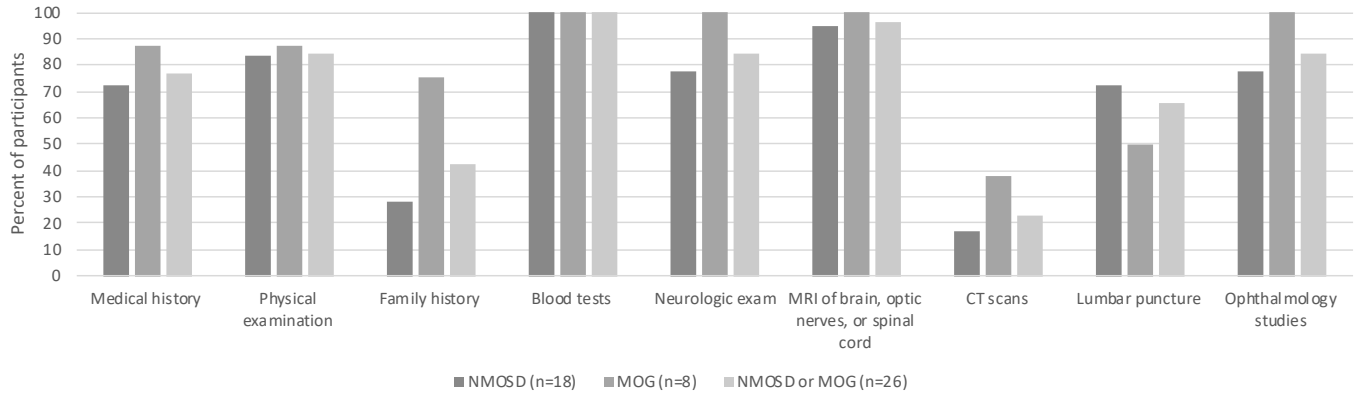

Figure 3.9: Diagnostic tests

Time from diagnostic test to diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis (Table 3.13, Figure 3.10).

NMOSD

Participants with NMOSD were most commonly diagnosed more than four weeks (including over a

year) after diagnostic tests (n=8, 44.45%). There were 10 participants (55.56%) who waited less than two weeks.

MOG

The majority of Participants with MOG were diagnosed more than four weeks (including over a year) after diagnostic tests (n=6, 75.00%). There were two participants (25.00%) who waited less than two weeks.

NMOSD or MOG

Overall, for participants with NMOSD or MOG, the majority of participants were diagnosed more than four weeks (including over a year) after diagnostic tests (n=14, 53.85%). There were 12 participants (46.15%) who waited less than two weeks.

Table 3.13: Time from diagnostic test to diagnosis

Time from diagnosis test to diagnosis	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Diagnosed immediately at the consultation	2	11.11	0	0.00	2	7.69
Less than 1 week	5	27.78	1	12.50	6	23.08
Between 1 and 2 weeks	3	16.67	1	12.50	4	15.38
Between 2 and 3 weeks	0	0.00	0	0.00	0	0.00
Between 3 and 4 weeks	0	0.00	0	0.00	0	0.00
4 weeks or more	5	27.78	4	50.00	9	34.62
More than a year	3	16.67	2	25.00	5	19.23

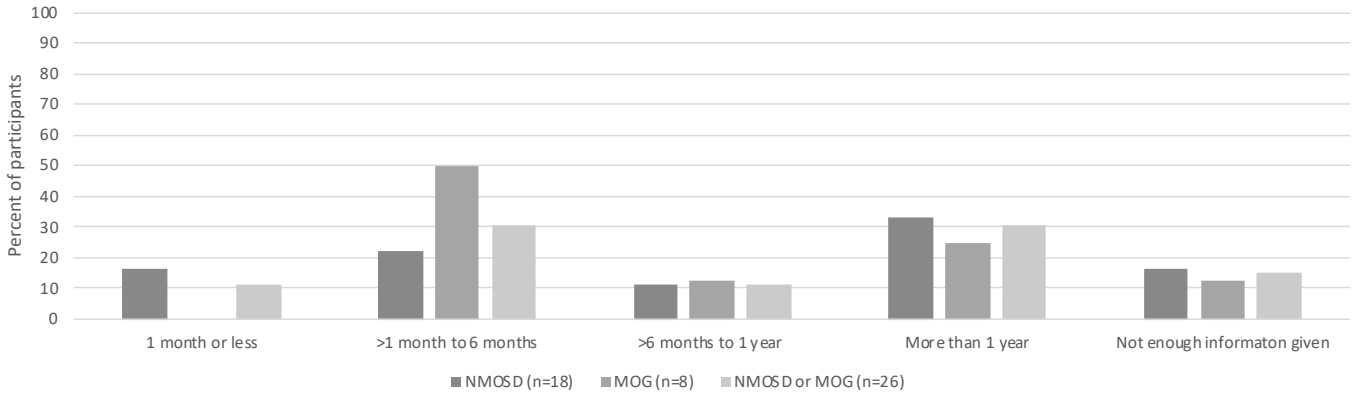

Figure 3.10: Time from diagnostic test to diagnosis

Time from symptoms to diagnosis

Participants were asked in the online questionnaire approximately when they first noticed symptoms, and when they were diagnosed. When at least the month and year was estimated for both noticing symptoms and being diagnosed, the time between noticing symptoms and being diagnosed was calculated (Table 3.14, Figure 3.11).

NMOSD

Participants with NMOSD were most commonly diagnosed more than a year after first noticing symptoms (n=6, 33.33%), there were two participants diagnosed between six and 12 months after noticing symptoms (n=2, 11.11%), four participants (22.22%) diagnosed between one and six months after noticing symptoms, and three (16.67%) diagnosed within one month after noticing symptoms.

MOG

Half of the participants with MOG were between one and six months of noticing symptoms (n=4, 50.00%), one participant (12.50%) diagnosed between six and 12 months after noticing symptoms, and two participants (25.00%) diagnosed after a year from noticing symptoms.

NMOSD or MOG

Overall, participants with NMOSD or MOG most commonly diagnosed more than a year after first noticing symptoms (n=8, 30.77%), or between one and six months after noticing symptoms (n=8, 30.77%). There were three (11.54%) participants diagnosed between six and 12 months after noticing symptoms, and three (11.54%) diagnosed within one month after noticing symptoms.

Table 3.14: Time from symptoms to diagnosis

Time from symptoms to diagnosis	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
1 month or less	3	16.67	0	0.00	3	11.54
>1 month to 6 months	4	22.22	4	50.00	8	30.77
>6 months to 1 year	2	11.11	1	12.50	3	11.54
More than 1 year	6	33.33	2	25.00	8	30.77
Not enough informaton given	3	16.67	1	12.50	4	15.38

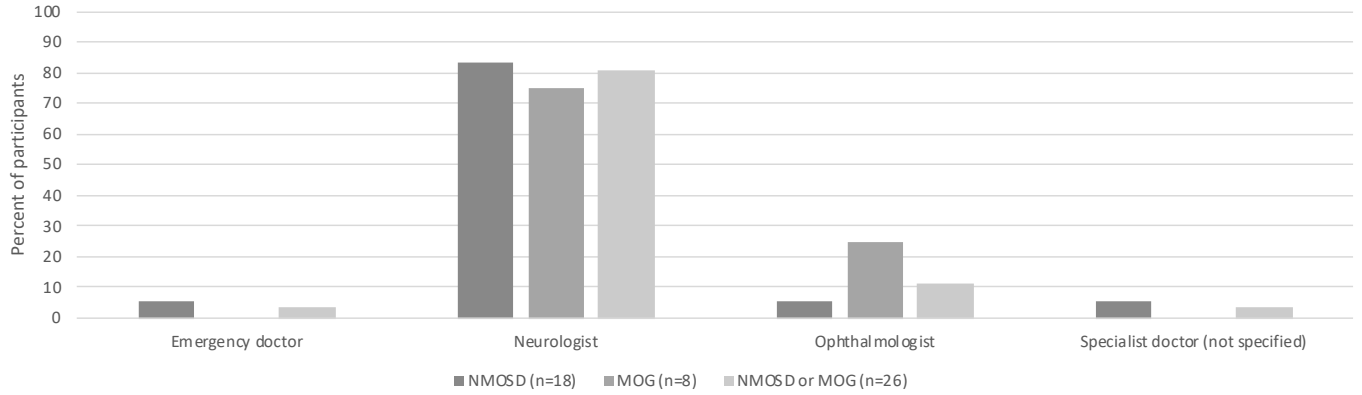

Figure 3.11: Time from symptoms to diagnosis

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis (Tables 3.15 and 3.16, Figures 3.12 and 3.13).

NMOSD

The majority of participants with NMOSD were diagnosed by a neurologist (n=15, 83.33%). Other healthcare professionals that gave the diagnosis included an emergency doctor (n=1, 5.56%), and ophthalmologist (n=1, 5.56%).

Over half of the participants with NMOSD were diagnosed at hospital (n=10, 55.56%). Other participants were diagnosed at the specialist's clinic (n=6, 33.33%), and two participants (11.11%) received their diagnosis over the phone.

MOG

The majority of participants with MOG were diagnosed by a neurologist (n=6, 75.00%), and there were two participants diagnosed by an ophthalmologist (n=2, 25.00%).

The majority of participants with MOG were diagnosed at hospital (n=5, 62.50%), and there were three participants were diagnosed at the specialist's clinic (37.50%).

NMOSD or MOG

Overall, participants with NMOSD or MOG were most commonly diagnosed by a neurologist (n=21, 80.77%). Other healthcare professionals that gave the diagnosis included an emergency doctor (n=1, 3.85%), and ophthalmologist (n=3, 11.54%).

Over half of NMOSD or MOG participants were diagnosed at hospital (n=15, 57.69%). Other participants were diagnosed at the specialist's clinic (n=9, 34.62%), and two participants (7.69%) received their diagnosis over the phone.

Table 3.15: Diagnosis provider

Diagnosis provider	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Emergency doctor	1	5.56	0	0.00	1	3.85
Neurologist	15	83.33	6	75.00	21	80.77
Ophthalmologist	1	5.56	2	25.00	3	11.54
Specialist doctor (not specified)	1	5.56	0	0.00	1	3.85

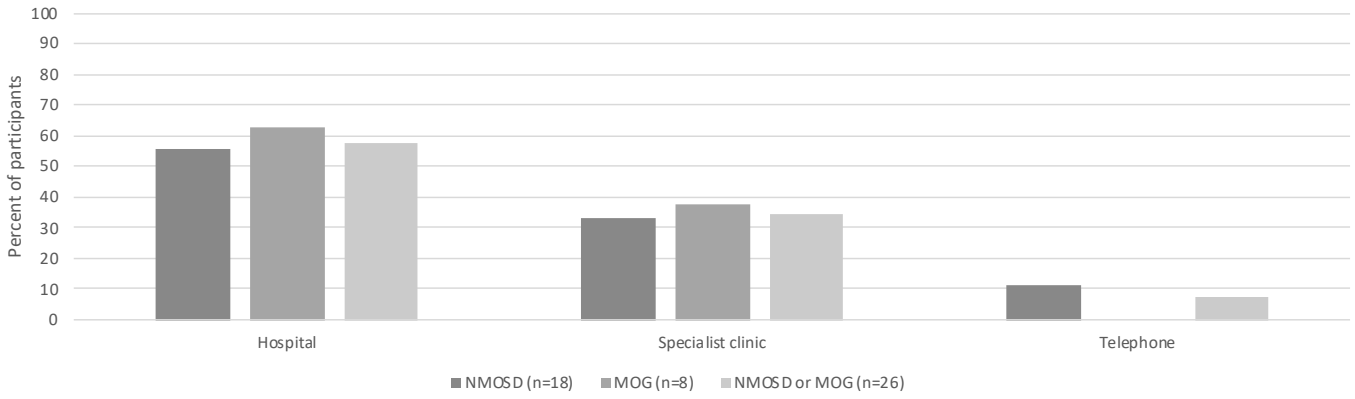

Figure 3.12: Diagnosis provider

Table 3.16: Diagnosis location

Diagnosis location	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Hospital	10	55.56	5	62.50	15	57.69
Specialist clinic	6	33.33	3	37.50	9	34.62
Telephone	2	11.11	0	0.00	2	7.69

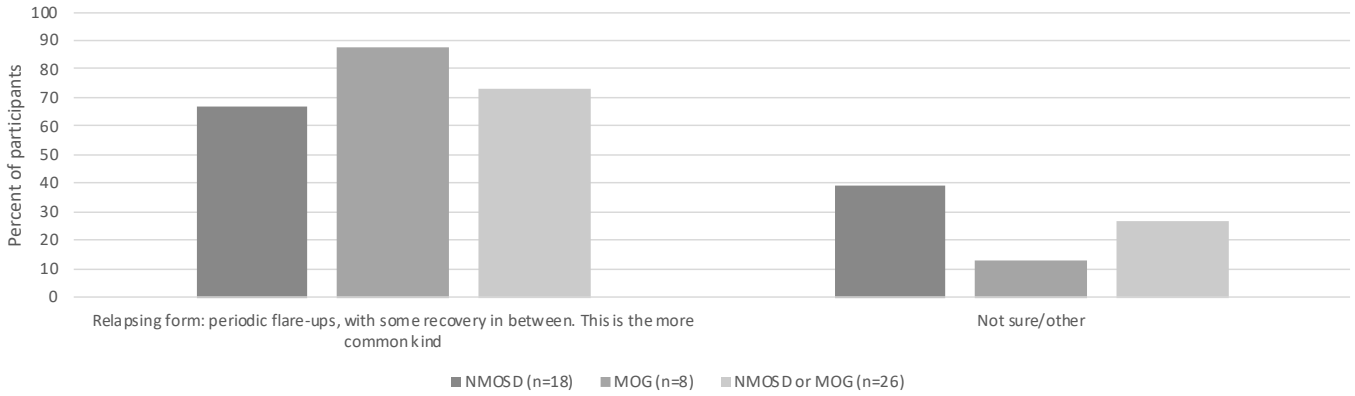

Figure 3.13: Diagnosis location

Form of condition

In the online questionnaire, participants were asked if they were diagnosed with relapsing or monophasic form. No participants were diagnosed with the monophasic form (Table 3.17, Figure 3.14)

NMOSD

There were 12 participants (66.67%) with NMOSD who were diagnosed with the relapsing form, and 7 participants who were not sure (38.89%).

MOG

There were 7 participants (87.50%) with MOG who were diagnosed with the relapsing form, and one participant who was not sure (12.50%).

NMOSD and MOG

Overall, there were 19 participants (73.08%) with NMOSD or MOG who were diagnosed with the relapsing form, and 8 participants who were not sure (30.77%).

Table 3.17: Form of condition

Form of condition	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Relapsing form: periodic flare-ups, with some recovery in between. This is the more common kind	12	66.67	7	87.50	19	73.08
Not sure/other	7	38.89	1	12.50	8	30.77

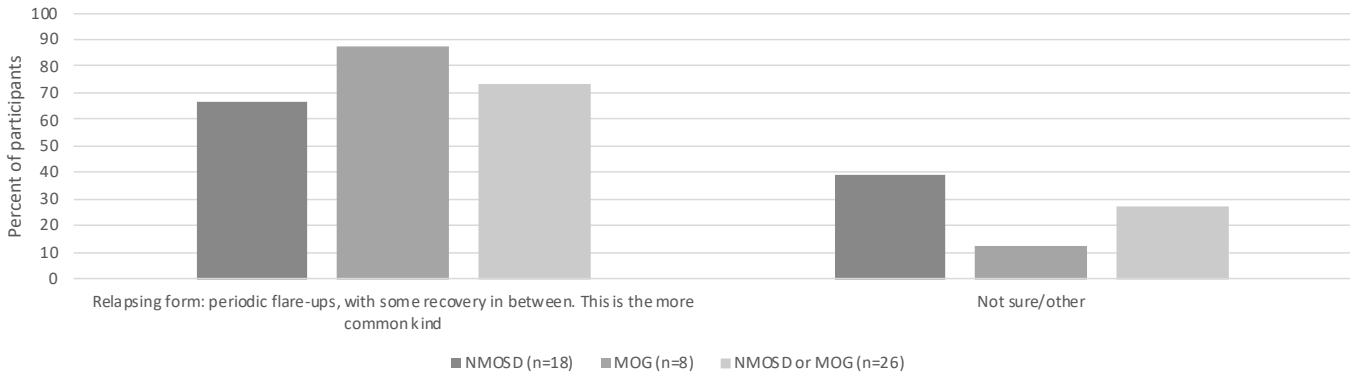

Figure 3.14: Form of condition

Age at diagnosis

Participants were asked in the online questionnaire how old they were when diagnosed (Table 3.18, Figure 3.15).

NMOSD

Most of the participants with NMOSD were diagnosed when they were 40 years or older (n=12, 66.67%), and there were six participants (33.33%) who were diagnosed when they were younger that 40 years.

MOG

Half of the participants with MOG were diagnosed aged under 40, and half diagnosed at 40 years or older.

NMOSD or MOG

Overall, the majority of participants with NMOSD or MOG were diagnosed when they were 40 years or older (n=16, 61.54%), and there were 10 participants (38.46%) who were diagnosed when they were younger that 40 years.

Table 3.18: Age at diagnosis

Age at diagnosis	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Under 40 years	6	33.33	4	50.00	10	38.46
40 or older	12	66.67	4	50.00	16	61.54

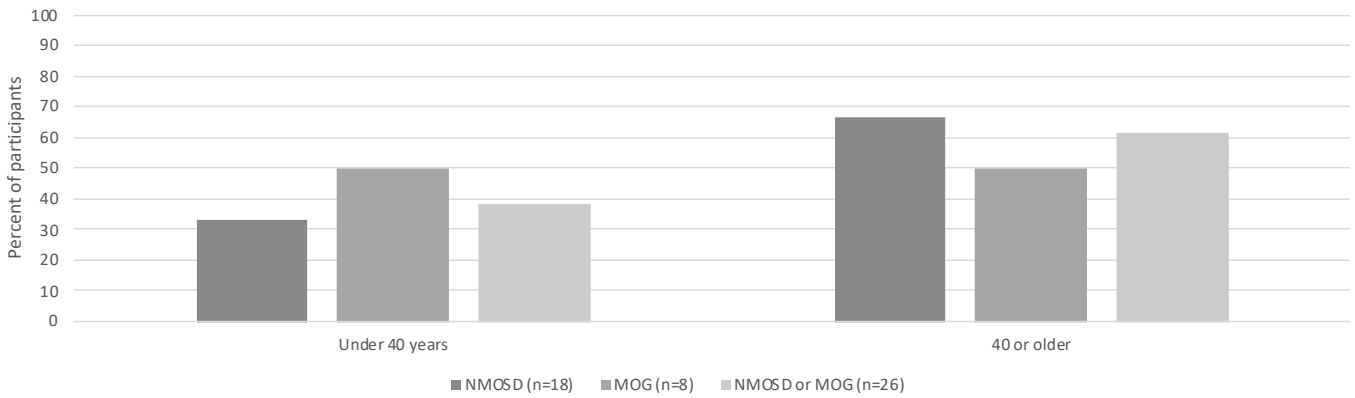

Figure 3.15: Age at diagnosis

Number of relapses

Participants were asked in the online questionnaire how many relapses they have had (Table 3.19, Figure 3.16).

NMOSD

Participants with NMOSD most commonly had one or two relapses, or three or four relapses (n=6, 33.33%). There were three participants (16.67%) that had more than five relapses, and three participants (16.67%) that had no relapses.

MOG

All participants with MOG had at least one relapse. The majority of participants had one or two relapses (n=6, 75.00%).

NMOSD or MOG

Overall, almost half of participants with NMOSD or MOG had one or two relapses (n=12, 46.15%). There were seven participants (26.92%) that had three or four relapses, four (15.38%) that had more than five relapses, and three participants (11.54%) that had no relapses.

Table 3.19: Number of relapses

Number of relapses	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
No relapses	3	16.67	0	0.00	3	11.54
1 to 2	6	33.33	6	75.00	12	46.15
3 to 4	6	33.33	1	12.50	7	26.92
5 or more	3	16.67	1	12.50	4	15.38

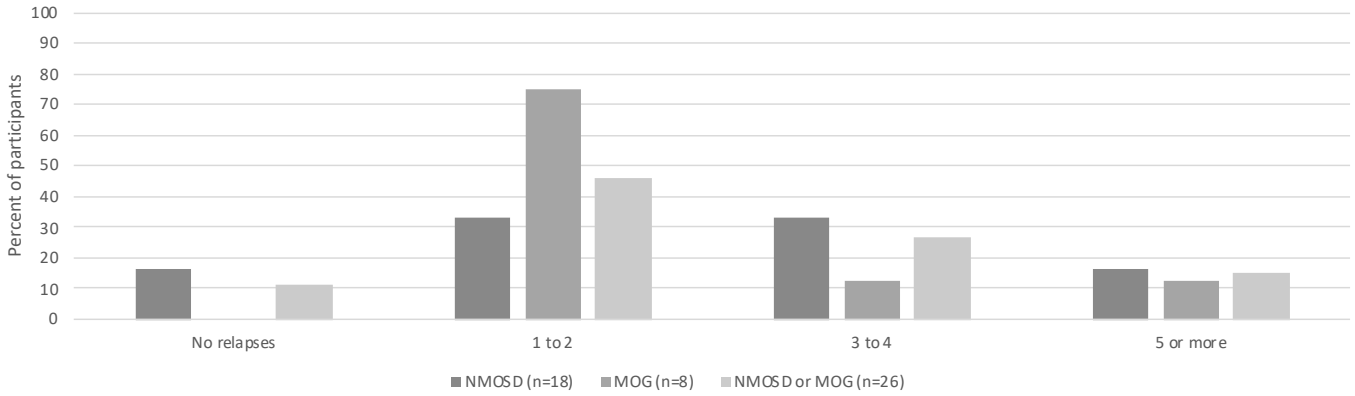

Figure 3.16: Number of relapses

Year of diagnosis

Participants noted in the online questionnaire approximately when they were diagnosed. The year of diagnosis is present in Table 3.20 and Figure 3.17

NMOSD

Participants with NMOSD were most commonly diagnosed during 2016 to 2018 (n=7, 38.89%), there were five participants (27.78%) diagnosed during 2019 to 2020, four participants (22.22%) diagnosed between 2011 and 2015, and two participants (11.11%) diagnosed in 2010 or earlier.

MOG

Over half of the participants with MOG were diagnosed in 2019 or 2020 (n=5, 62.50%). There were two participants (25.00%) diagnosed between 2016 and 2018, and one (12.50%) between 2011 and 2015.

NMOSD and MOG

Overall, participants with NMOSD or MOG were most commonly diagnosed in 2019 or 2020 (n=10 38.46%), there were nine participants (34.62%) diagnosed during 2016 to 2018, five participants (19.23%) diagnosed between 2011 and 2015, and two participants (7.69%) diagnosed in 2010 or earlier.

Table 3.20: Year of diagnosis

Year of diagnosis	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
2010 or before	2	11.11	0	0.00	2	7.69
2011 to 2015	4	22.22	1	12.50	5	19.23
2016 to 2018	7	38.89	2	25.00	9	34.62
2019 to 2020	5	27.78	5	62.50	10	38.46

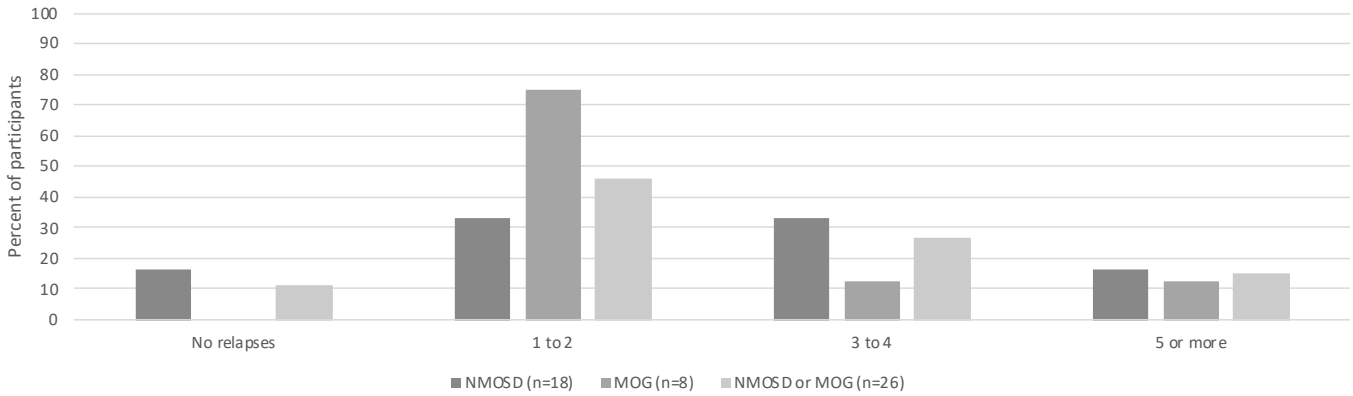

Figure 3.17: Year of diagnosis

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. There were eight participants (44.44%) that described knowing nothing at diagnosis and this was followed by seven participants (38.89%) who described knowing very little. There were 10 participants (55.56%) who described knowing/not knowing about the condition but no specific reason for the level of knowledge. While not reported in the tables below, it is interesting to note that 9 NMOSD participants (50.00%) described their understanding at diagnosis as their condition being similar to Multiple Sclerosis.

Participant describes knowing nothing about the condition at diagnosis

Absolutely nothing. Participant NMO_010

Nothing. When I was diagnosed, no. Nothing. Participant NMO_001

I knew nothing about it. Participant NMO_008

Participant describes knowing very little about the condition at diagnosis

Not a lot. It was painted as a very, very scary condition back in 2010 because it was all likely way worse than MS. It took a long time to be okay with it and I suppose with the medication and after time, not having a relapse that made me feel better but I didn't know much. Participant NMO_010

Not really a lot. When I was first diagnosed I was told very, very little. All I was told was that there was no definitive cure for the disease and no definitive cause, that was all I was told. It was more from groups on Facebook that's where I found help, which was absolutely perfect. Participant NMO_009

Not a lot, unfortunately. His cousin has MS, and then I remember when I was pre-school age, we were living in a block of flats. There was one young woman who got diagnosed with MS. I was too young and I didn't understand, but I do always remember that. I always see her face when I hear about MS. Participant NMOCA_003

Participant describes knowing/not knowing about the condition but no specific reason for the level of knowledge

Nothing. Nothing at all. Hadn't heard of it. Participant NMOCA_022

I knew nothing about it. Participant NMO_008

Nothing. Absolutely nothing. Participant NMOCA_007

Participant describes knowing little about the condition at diagnosis but began researching the condition before or throughout the diagnostic process

Only what I had googled when NAME DOCTOR had sent me for this blood test. I then had a look on Google what NMO was and so when he rang me, he was going on holiday that day so he knew I would want to know the result as soon as possible and he booked me with a neurologist for the Monday and that was the Thursday he rang me. Participant NMO_006

Only what was found on the internet, and back then years ago, it was, to be honest, quite traumatic. You would read statistics that were quite frightening that you had a 50% chance of dying of respiratory failure within five years. That was frightening. Participant NMO_004

I knew a little bit with some things that if you looked up on YouTube or something of MS and NMO would come up, but not much information. Just a very, very little bit. [chuckles] I read things like that, and it was like, "I hope it's not that." [laughs] It's like, "Oh, that's a bit scary." I had a very, very small understanding of it, but not that much. Participant NMO_012

Table 3.21: Understanding of disease at diagnosis

Understanding of disease at diagnosis	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes knowing/not knowing about the condition but no specific reason for the level of knowledge	10	55.56	6	66.67	4	44.44	5	62.50	5	50.00	4	44.44	6	66.67
Participant describes knowing little about the condition at diagnosis but began researching the condition before or throughout the diagnostic process	4	22.22	1	11.11	3	33.33	2	25.00	2	20.00	3	33.33	1	11.11
Participant describes knowing nothing about the condition at diagnosis	8	44.44	5	55.56	3	33.33	5	62.50	3	30.00	3	33.33	5	55.56
Participant describes knowing very little about the condition at diagnosis	7	38.89	2	22.22	5	55.56	3	37.50	4	40.00	4	44.44	3	33.33

Understanding of disease at diagnosis	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes knowing/not knowing about the condition but no specific reason for the level of knowledge	10	55.56	6	60.00	4	50.00	2	33.33	8	66.67	4	57.14	6	54.55
Participant describes knowing little about the condition at diagnosis but began researching the condition before or throughout the diagnostic process	4	22.22	3	30.00	1	12.50	2	33.33	2	16.67	1	14.29	3	27.27
Participant describes knowing nothing about the condition at diagnosis	8	44.44	4	40.00	4	50.00	1	16.67	7	58.33	3	42.86	5	45.45
Participant describes knowing very little about the condition at diagnosis	7	38.89	5	50.00	2	25.00	3	50.00	4	33.33	3	42.86	4	36.36

Understanding of disease at diagnosis	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes knowing/not knowing about the condition but no specific reason for the level of knowledge	10	55.56	6	75.00	16	61.54	6	60.00	8	50.00	2	100.00	1	33.33	9	60.00
Participant describes knowing little about the condition at diagnosis but began researching the condition before or throughout the diagnostic process	4	22.22	1	12.50	5	19.23	0	0.00	4	25.00	0	0.00	2	66.67	2	13.33
Participant describes knowing nothing about the condition at diagnosis	8	44.44	5	62.50	13	50.00	8	80.00	7	43.75	1	50.00	0	0.00	8	53.33
Participant describes knowing very little about the condition at diagnosis	7	38.89	2	25.00	9	34.62	1	10.00	6	37.50	1	50.00	3	100.00	4	26.67

Table 3.22: Understanding of disease at diagnosis (Subgroup variations)

Understanding of disease at diagnosis	More frequent	Less frequent
Participant describes knowing/not knowing about the condition but no specific reason for the level of knowledge	Fewer relapses Good to very good physical function Higher socioeconomic status	More relapses Moderate to very poor physical function Mid to low socioeconomic status
Participant describes knowing nothing about the condition at diagnosis	Fewer relapses Low to moderate fear Good to very good physical function	More relapses High to very high fear Moderate to very poor physical function Higher socioeconomic status
Participant describes knowing very little about the condition at diagnosis	More relapses Trade or high school	Fewer relapses University

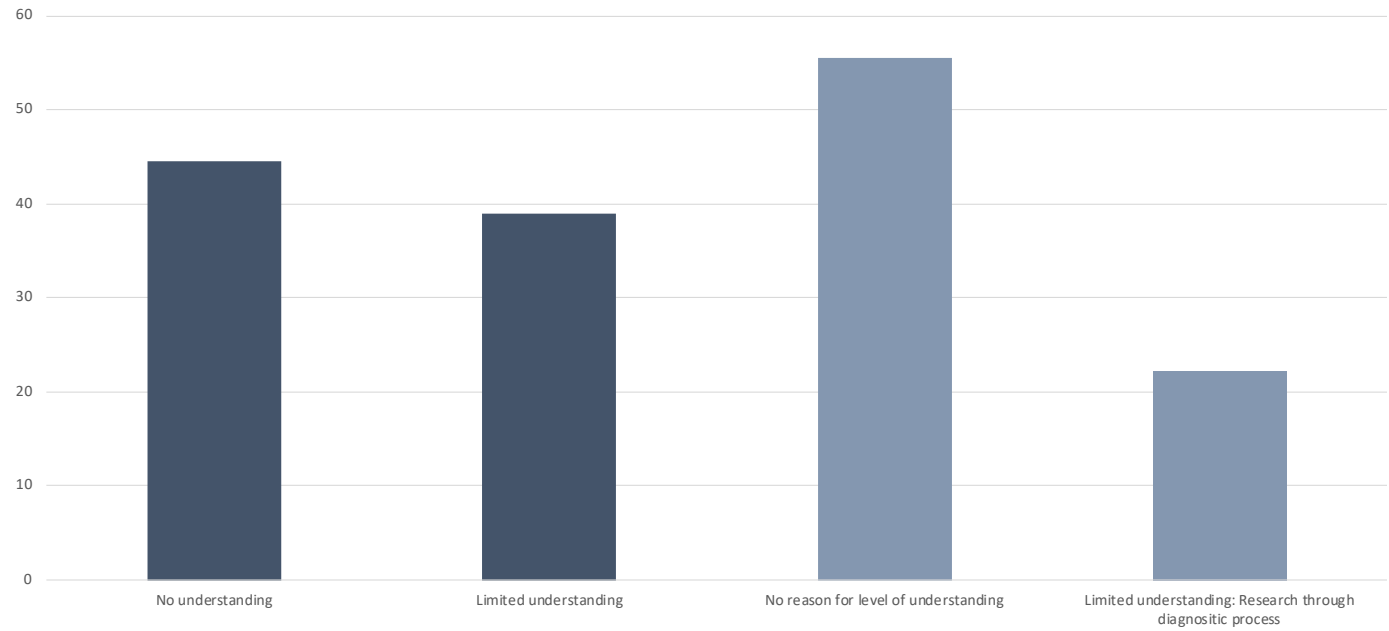

Figure 3.18 Understanding of disease at diagnosis

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis (Table 3.23, Figure 3.19).

NMOSD

The majority of participants with NMOSD had no support at the time of diagnosis (n=13, 72.22%), there were three participants (16.67%) that had enough support, and two participants (11.11%) that had some support, but not enough.

MOG

The majority of participants with MOG had no support at the time of diagnosis (n=5, 62.50%), there was one participant (12.50%) that had enough support, and two participants (25.00%) that had some support, but not enough.

NMOSD or MOG

Overall, the majority of participants with NMOSD or MOG had no support at the time of diagnosis (n=18, 69.23%), there were four participants (15.38%) that had enough support, and four participants (15.38%) that had some support, but not enough.

Table 3.23: Emotional support at diagnosis

Emotional support at diagnosis	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Enough support	3	16.67	1	12.50	4	15.38
Some support but it wasn't enough	2	11.11	2	25.00	4	15.38
No support	13	72.22	5	62.50	18	69.23

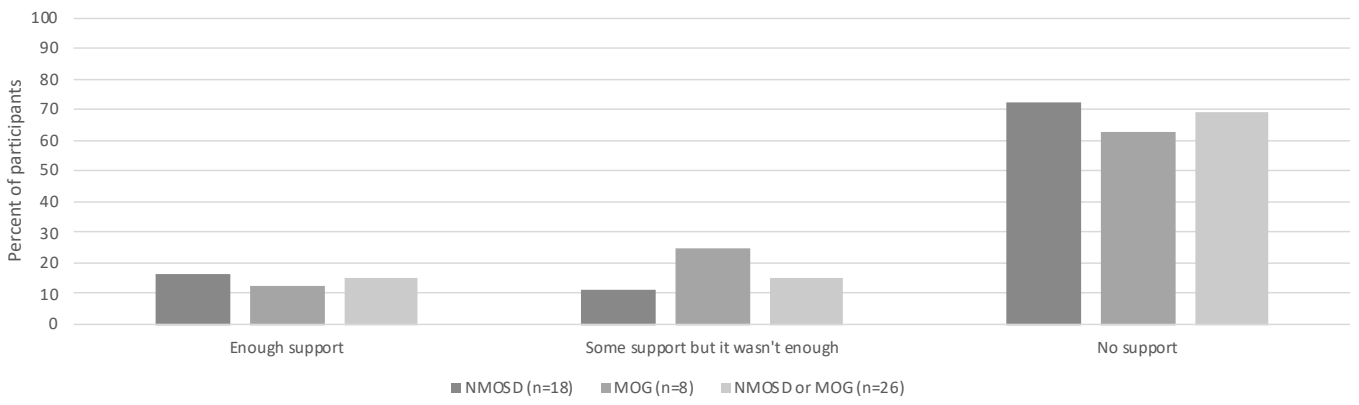

Figure 3.19: Emotional support at diagnosis

Information at diagnosis

Participants were asked in the online questionnaire how much information they or their family received at diagnosis (Table 3.24, Figure 3.20).

NMOSD

Half of participants with NMOSD had some information, but not enough (n=9, 50.00%), there were eight participants (44.44%) had no information, and one participant (5.56%) that had enough information.

MOG

Half of participants with MOG no information (n=4, 50.00%), there were three participants (37.50%) that had some information , but not enough, and one participant (12.50%) that had enough information.

NMOSD or MOG

Overall, participants with NMOSD or MOG most commonly had no information at diagnosis (n=12, 46.15%), or some information but not enough (n=12, 46.15%), and there were two participants (7.69%) that had enough information.

Table 3.24: Information at diagnosis

Information at diagnosis	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Enough information	1	5.56	1	12.50	2	7.69
Some information but it wasn't enough	9	50.00	3	37.50	12	46.15
No information	8	44.44	4	50.00	12	46.15

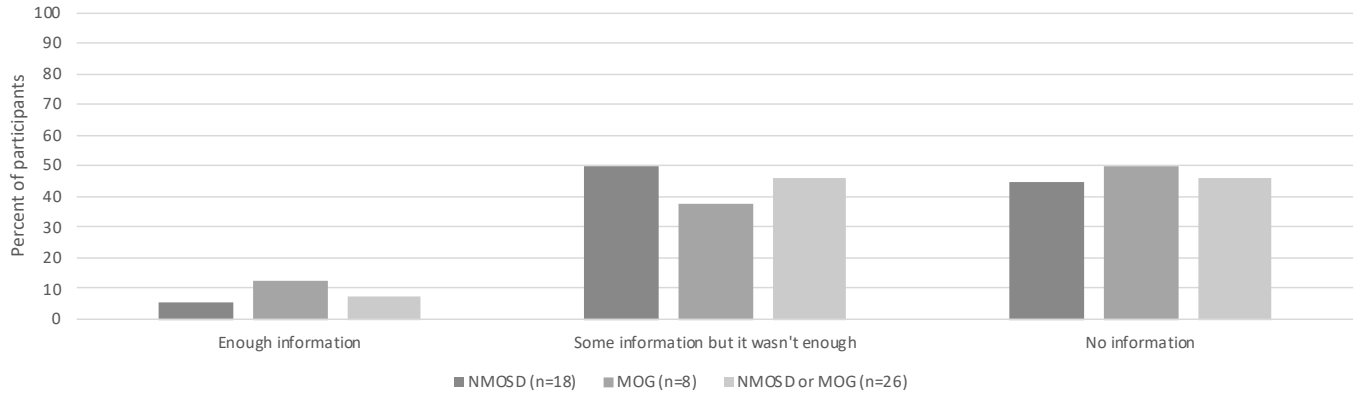

Figure 3.20: Information at diagnosis

Costs at diagnosis

Participants noted in the online questionnaire the amount of out of pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests (Table 3.25, Figure 3.21). For those that could remember how much they spent, a follow up question was asked about the burden the costs at diagnosis (Table 3.26, Figure 3.22).

NMOSD

There were five participants with NMOSD that had no out of pocket expenses (27.78%), three participants (16.67%) that had spent more than $1,000, and 10 participants (55.56%) that were not sure of the amount they spent.

Of the eight participants that could recall the amount they spent, the burden of costs were significant or very significant for four participants (50.00%), a moderate burden for two participants (25.00%), and slightly or not at all significant for two participants (25.00%).

MOG

There were four participants (50.00%) with MOG that had no out of pocket expenses , two participants (25.00%) that had spent more than $1,000, and two participants (25.00%) that were not sure of the amount they spent.

All of the participants with MOG that could recall how much they spent at diagnosis found that cost a slightly significant burden

NMOSD or MOG

There were nine participants (34.62%) with MOG that had no out of pocket expenses , five participants (19.23%) that had spent more than $1,000, and 12 participants (46.15%) that were not sure of the amount they spent.

Overall, for participants with NMOSD or MOG hat could recall the amount they spent, the burden of costs were significant or very significant for four participants (33.33%), a moderate burden for two participants (16.67%), and slightly or not at all significant for six participants (50.00%).

Table 3.25: Costs at diagnosis

Out of pocket expenses for diagnostic tests	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
$0	5	27.78	4	50.00	9	34.62
More than $1000	3	16.67	2	25.00	5	19.23
Not sure	10	55.56	2	25.00	12	46.15

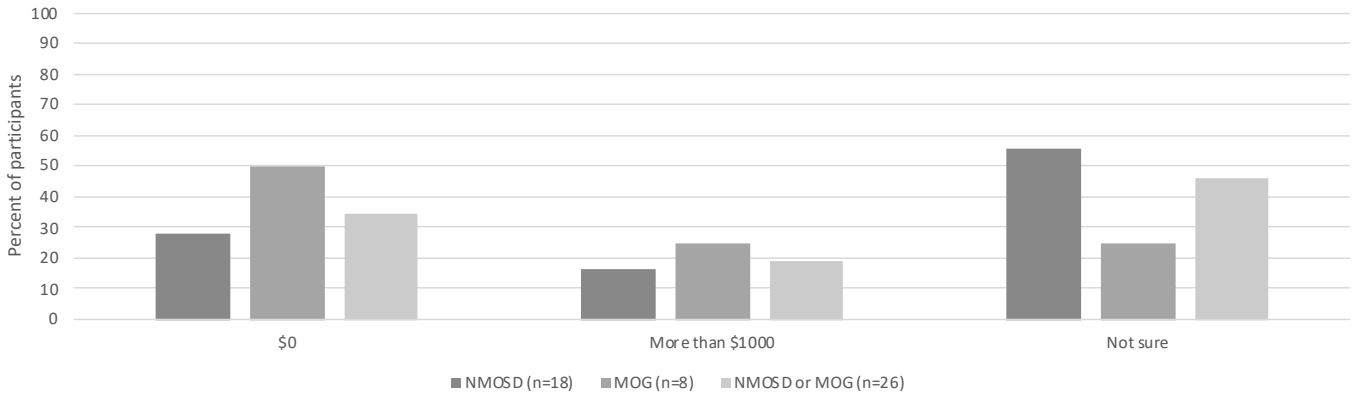

Figure 3.21: Costs at diagnosis

Table 3.26: Burden of diagnostic costs

Burden of diagnostic costs	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=8)	Percent	Number (n=4)	Percent	Number (n=12)	Percent
Not at all significant	1	12.50	0	0.00	1	8.33
Slightly significant	1	12.50	4	100.00	5	41.67
Somewhat significant	2	25.00	0	0.00	2	16.67
Moderately significant	3	37.50	0	0.00	3	25.00
Extremely significant	1	12.50	0	0.00	1	8.33

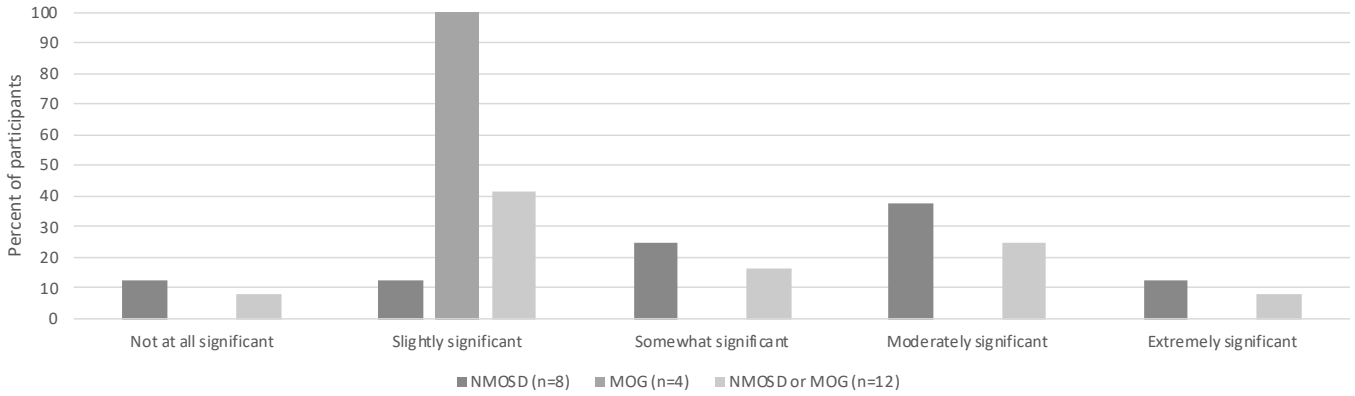

Figure 3.22: Burden of diagnostic costs

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did. There were no participants that brought the topic up with their doctor (Table 3.27, Figure 3.23).

NMOSD

The majority of participants with NMOSD had never had a conversation about biomarker/genomic/gene testing that might be relevant to treatment, (n=13, 72.22%). There were five participants (27.78%) whose doctor brought up the topic with them.

MOG

The majority of participants with MOG had never had a conversation about biomarker/genomic/gene testing that might be relevant to treatment, (n=7, 87.50%). There was one participant (12.50%) whose doctor brought up the topic with them.

NMOSD and MOG

The majority of participants with NMOSD or MOG had never had a conversation about biomarker/genomic/gene testing that might be relevant to treatment, (n=20, 76.92%). There were six participants (23.08%) whose doctor brought up the topic with them.

Table 3.27: Discussions about biomarkers

Discussions about biomarkers	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Participant brought up the topic with doctor for discussion	0	0.00	0	0.00	0	0.00
Doctor brought up the topic with participant for discussion	5	27.78	1	12.50	6	23.08
Participant had no discussion about this type of test	13	72.22	7	87.50	20	76.92

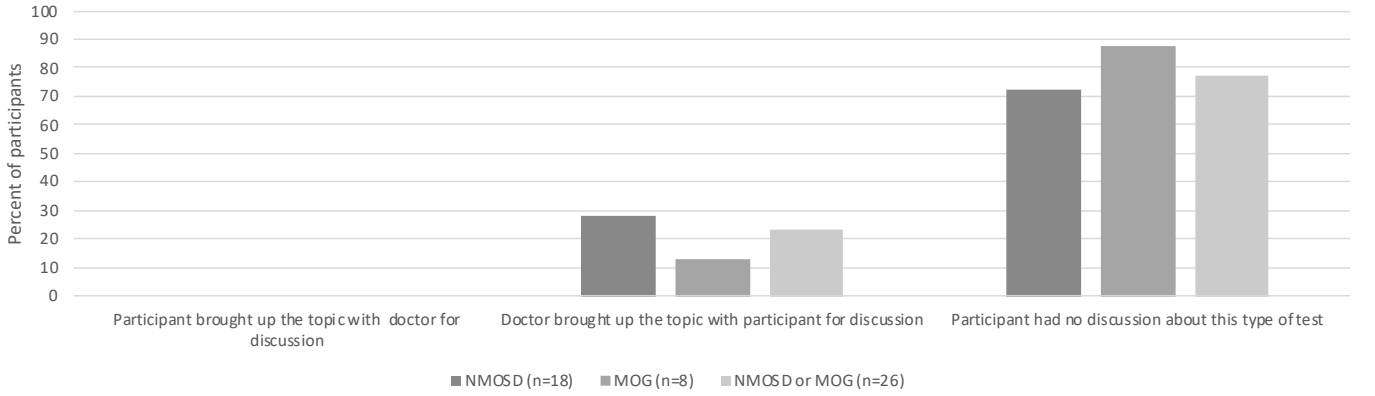

Figure 3.23: Discussions about biomarkers

Experience of genetic tests and biomarkers

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test. There were no participants that paid for their test, and there were no participants that were not interested in having this sort of test (Table 3.28, Figure 3.24).

NMOSD

The majority of participants with NMOSD did not have any genetic or biomarker tests but would like to (n=11, 61.11%). There were six participants (33.33%) that had tests and paid out of pocket for it, and one participant (5.56%) that had the test through a clinical trial

MOG

The majority of participants with MOG did not have any genetic or biomarker tests but would like to (n=7, 87.50%). There was one participant (12.50%) that had tests and paid out of pocket for it.

NMOSD or MOG

The majority of participants with NMOSD or MOG did not have any genetic or biomarker tests but would like to (n=18, 69.23%). There were seven participants (26.92%) that had tests and paid out of pocket for it, and one participants (3.85%) that had the test through a clinical trial.

Table 3.28: Experience of genetic tests and biomarkers

Experience of genetic tests and biomarkers	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Participant had this test and did not have to pay out of pocket for it	6	33.33	1	12.50	7	26.92
Participant had test through a clinical trial	1	5.56	0	0.00	1	3.85
Participant had this type of test and paid for it myself	0	0.00	0	0.00	0	0.00
Participant did not have this test and is not interested in it	0	0.00	0	0.00	0	0.00
Participant did not have this test but would like to	11	61.11	7	87.50	18	69.23

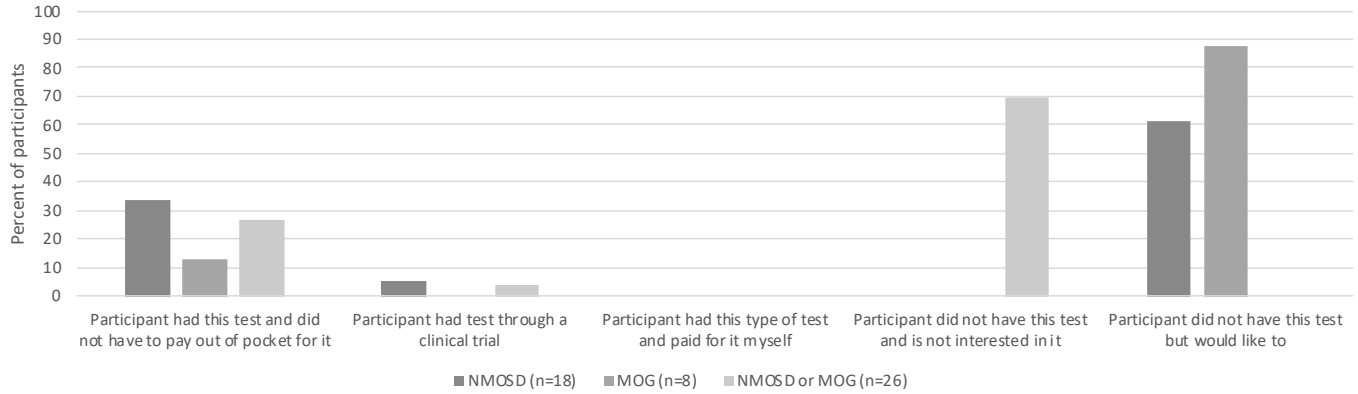

Figure 3.24: Experience of genetic tests and biomarkers

Specific biomarkers or genetic markers

For the final question about biomarkers, participants were asked about specific biomarkers that they had that are relevant to their condition (Table 3.29, Figure 3.25).

NMOSD

There were seven participants (38.89%) with NMOSD that were not sure if they had specific biomarkers or genetic markers. Five participants (27.78%) had a family history of auto immune diseases, and two had a family history of NMOSD (11.11%). There were 6 participants (33.33%) that were Aquaporin-4, AQP4-IgG, or NMO-IgG positive, and two (11.11%) that were MOG-IgG positive.

MOG

There were two participants (25.00%) with MOG that were not sure if they had specific biomarkers or genetic markers. Two participants (25.00%) had a family history of auto immune diseases. There were five participants (62.50%) that were MOG-IgG positive.

NMOSD or MOG

Overall, there were nine participants (34.62%) with NMOSD or MOG that were not sure if they had specific biomarkers or genetic markers. Seven participants (26.92%) had a family history of auto immune diseases, and two had a family history of NMOSD (7.69%). There were 6 participants (23.08%) that were Aquaporin-4, AQP4-IgG, or NMO-IgG positive, and seven (26.92%) that were MOG-IgG positive.

Table 3.29: Specific biomarkers or genetic markers

Specific biomarkers or genetic markers	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Aquaporin-4, AQP4-IgG, or NMO-IgG Negative	3	16.67	0	0.00	3	11.54
Aquaporin-4, AQP4-IgG, or NMO-IgG Postive	6	33.33	0	0.00	6	23.08
MOG-IgG Negative	2	11.11	0	0.00	2	7.69
MOG-IgG Postive	2	11.11	5	62.50	7	26.92
Family history of auto immune conditions	5	27.78	2	25.00	7	26.92
Family history of NMOSD	2	11.11	0	0.00	2	7.69
Not sure	7	38.89	2	25.00	9	34.62

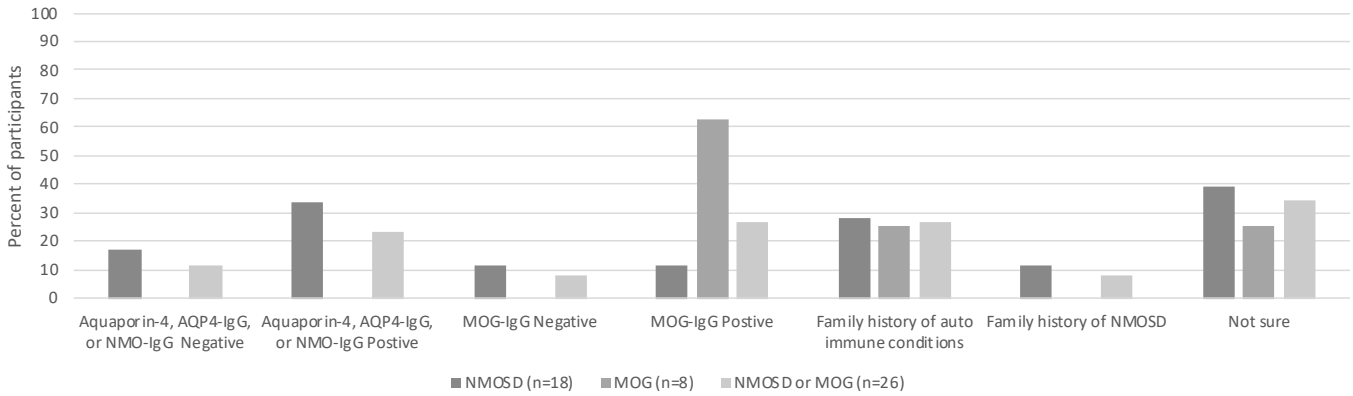

Figure 3.25: Specific biomarkers or genetic markers

Understanding of prognosis

Participants were asked in the structured interview to describe what their understanding of prognosis was. There were five participants (27.78%) who described their prognosis in relation to the long-term permanent effects they have suffered from it.

Participant describes their prognosis in relation to the long term or permanent effects they have suffered from it

At this very moment in time I have still poor vision in my right eye and I also during the space of two days of being diagnosed with the blood test, I had a TM episode so I now have a lesion from T5 to T10 on my spine, so I walk with a walker or a stick if I've got my husband or somebody with me and it's only short. I have hand controls in my car now but fatigue and mobility and vision impairs me doing my old life, put it that way. I have a new life, which is okay. Participant NMO_006

Oh, goodness. Well, my peripheral vision has gone in both eyes. I'm legally blind in the right eye. I can't drive. Just doing standard chores around the house, like washing up, or just cooking things. I've got to sit down. I can't stand up for too long, but if I do-- What's the word? If I do do things, I've just got to keep on moving, but I've got to be careful that my body temperature doesn't go up because that's when I've got to lay down because it feels like I'm just going to faint, just drop. Participant NMO_012

I'm left with a slight pain, but I just move on from it. I just ignore it. I have some poor eyesight and I've lost some vision in my left but that's been for about probably five, six years now, so I'm used to it, and I went back to work full-time about four years ago. Participant NMO_017

Participant describes prognosis in relation to continuing with treatment to prevent an exacerbation/progression or deteriorations

Yes. I think with NMO, from what I understand, it's all about prevention, so it's really important to-- If you find the right immunosuppressant, you can live quite well, and you can pretty much-- As long as you can get on top of it early, from my understanding, and from what I've been through, I realised that it's very important that if something's going on, that you go and have treatments, like for example, steroids, IV steroids, and that helps you in the long term. Participant NMO_005

At the moment, at this stage, I just get Rituximab every six months. I'd have Rituximab and then a month after Rituximab, I'd have a blood test and they'd check if they got rid of all those markers or cells or whatever, then at six months I'd start doing blood tests again. As soon as they saw them coming back, they'd book me in and that might take two to three weeks to get in and get Rituximab. Participant NMO_015

Well, current outlook and prognosis is that we understand from the discussions that we've had with all the medical staff, that this will probably get to a point where it will progress into the spine, which we're hoping will not be for a few years off, and they're hopeful that that won't happen as well. Apparently where we've been told that there's lots of medical trials that they're trialling, they're trying a lot of stem cell therapy, but nothing is available to us as yet. We're just on a maintenance program. Participant NMOCA_007

Participant describes prognosis in relation to probable recurrence/cycle of recurrence

I don't know. My diagnosis was last November and a few weeks ago I just had a relapse. Of course, I'm upset about the relapse and I don't know where it's going. I'm still recovering from my last relapse a few weeks ago. No, I'm not hopeful about this condition at all. I know there's no cure. It's more worrying about what's the next relapse going to do? I think that's how I feel. Participant NMO_001

I just spoke to my neurologist with a video call about half an hour ago. They're not confident my condition will improve, but they said it can-- not to lose hope with it at all. At the moment it's stable as it is and they're just trying to stop any more relapses. Participant NMO_009

Participant describes prognosis in relation to it being positive: Condition is manageable with treatment

So, yes. I don't feel like I have a disease. I have Rituximab every six months. I do bloods and just keep going forward really. My prognosis in my opinion is that stress and my busy lifestyle will probably kill me before NMO will. Participant NMO_017

Well, if the medication keeps working, I can finish 10 days of running 10km a day which I've never done before in my life but that was a challenge I set myself. Things are pretty good at the moment. Participant NMO_002

Well, she has been on high doses of steroids. That's the treatment. They are doing another treatment for her which basically gives her immune system a boost and just at the moment, I can't think what the name of that is. That's helping her a lot because NAME PERSON CARED FOR's always suffered from an asthmatic condition and used to get quite a few flus and things like that throughout the time. Participant NMOCA_004

Table 3.30: Understanding of prognosis

Understanding of prognosis	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes their prognosis in relation to the long term or permanent effects they have suffered from it	5	27.78	2	22.22	3	33.33	2	25.00	3	30.00	2	22.22	3	33.33
Participant describes prognosis in relation to continuing with treatment to prevent an exacerbation/progression or deteriorations	3	16.67	2	22.22	1	11.11	2	25.00	1	10.00	1	11.11	2	22.22
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	2	11.11	2	22.22	0	0.00	1	12.50	1	10.00	2	22.22	0	0.00
Participant describes prognosis in relation to it being positive: Condition is manageable	2	11.11	1	11.11	1	11.11	2	25.00	0	0.00	0	0.00	2	22.22

Understanding of prognosis	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes their prognosis in relation to the long term or permanent effects they have suffered from it	5	27.78	4	40.00	1	12.50	2	33.33	3	25.00	1	14.29	4	36.36
Participant describes prognosis in relation to continuing with treatment to prevent an exacerbation/progression or deteriorations	3	16.67	0	0.00	3	37.50	1	16.67	2	16.67	1	14.29	2	18.18
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	2	11.11	1	10.00	1	12.50	1	16.67	1	8.33	1	14.29	1	9.09
Participant describes prognosis in relation to it being positive: Condition is manageable	2	11.11	0	0.00	2	25.00	0	0.00	2	16.67	1	14.29	1	9.09

Understanding of prognosis	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes their prognosis in relation to the long term or permanent effects they have suffered from it	5	27.78	0	0.00	5	19.23	1	10.00	4	25.00	1	50.00	1	33.33	4	26.67
Participant describes prognosis in relation to continuing with treatment to prevent an exacerbation/progression or deteriorations	3	16.67	6	75.00	9	34.62	2	20.00	3	18.75	0	0.00	0	0.00	3	20.00
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	2	11.11	6	75.00	8	30.77	2	20.00	1	6.25	1	50.00	1	33.33	1	6.67
Participant describes prognosis in relation to it being positive: Condition is manageable	2	11.11	0	0.00	2	7.69	4	40.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 3.32: Understanding of prognosis (Subgroup variations)

Understanding of prognosis	More frequent	Less frequent
Participant describes their prognosis in relation to the long term or permanent effects they have suffered from it	Trade or high school	University Aged 18 to 44

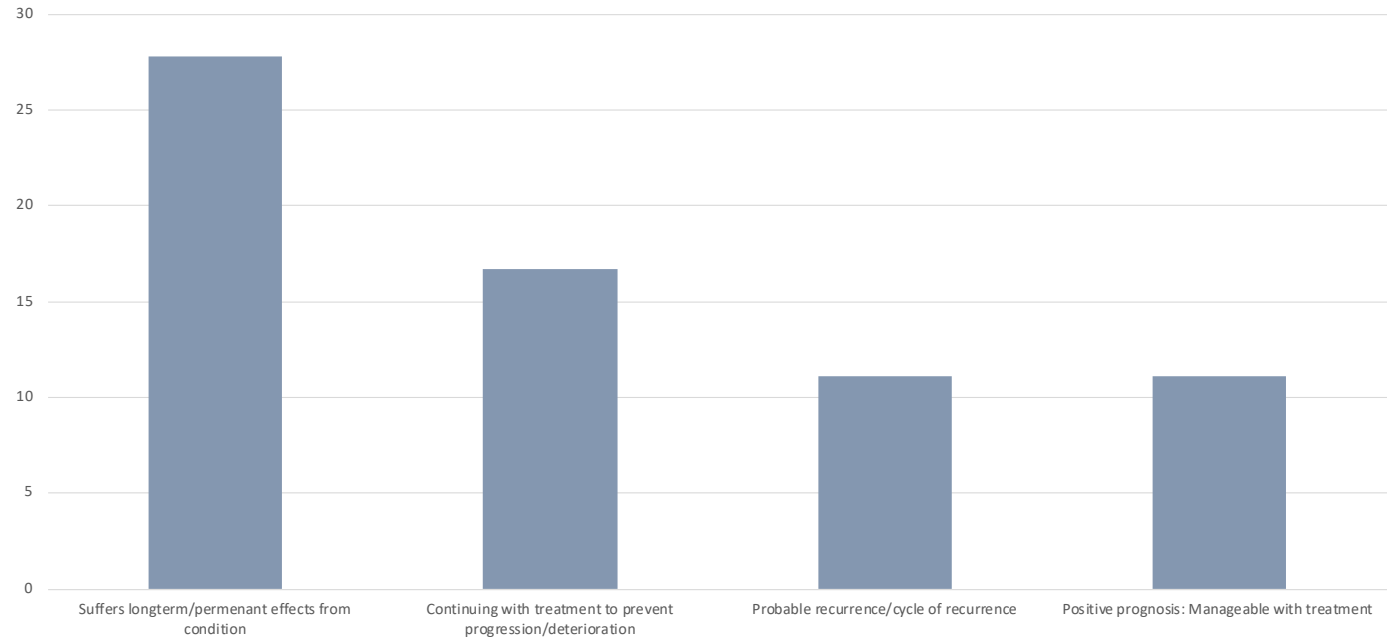

Figure 3.26: Understanding of prognosis