

Section 5

Treatment

Section 5: Experience of treatment

Main provider of treatment

Participants were asked in the online questionnaire who was the main healthcare professional that provided treatment and management of their condition. All participants had a neurologist as their main healthcare professional (n=26, 100.00%).

Access to healthcare professionals

Participants noted in the online questionnaire the healthcare professionals they had access to for the treatment and management of their condition. All participants with NMOSD had a neurologist for their condition. Over half of the participants had an ophthalmologist (n=10, 55.56%), general practitioner (n=10, 55.56%), and occupational therapist (n=10, 55.56%) to treat or manage their condition.

Respect shown

Participants were asked to think about how respectfully they were treated throughout their experience, this question was asked in the online questionnaire. The majority of participants with NMOSD indicated that they had been treated with respect throughout their experience, with the exception of one or two occasions (n=13, 72.22%), two participants (11.11%) felt they had been treated with respect, and three participants (16.67%) felt they had not been treated respectfully.

Health care system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient.

The majority of participants with NMOSD had health insurance (n=11, 61.11%), and the same number were asked if they wanted to be treated as a public or private patient. There were 12 participants (66.67%) that were asked if they had private health insurance

Most participants with NMOSD were treated as a public patient (n=12, 66.67%), there were five participants (27.78%) treated equally as a public and private patient, and one participant (5.56%) mostly as a private patient.

Most participants with NMOSD were treated in the public healthcare system (n=14, 77.78%), there were three participants (16.67%) treated equally in the public and private system, and one participant (5.56%) mostly in the private system.

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire. The first question was about having to delay or cancel healthcare appointments because they were unable to afford them. There were no participants that often or very often had to cancel appointments due to affordability. The majority of participants with NMOSD never or rarely cancelled their appointments due to cost (n=12, 66.67%), and six participants (33.33%) sometimes had to delay or cancel appointments due to affordability.

Filling prescriptions

Participants were then asked if they were unable to fill prescriptions for essential medicines due to cost. There were no participants that often or very often were unable to fill prescriptions due to affordability. The majority of participants with NMOSD never or rarely could not fill prescriptions due to cost (n=16, 88.89%), and two participants (11.11%) sometimes could not fill prescriptions due to cost.

Paying for basic essentials

Participants were asked as a result of their condition, if it made it difficult to pay for basic necessities such as housing, food and electricity. There were no participants that very often had trouble paying for basic essentials. The majority of participants with NMOSD never or rarely had trouble paying for basic essentials (n=12, 66.66%), and six participants (33.33%) sometimes or often had trouble paying for basic essentials.

Pay for additional carers

Participants were then asked if as a result of their condition, if they had to pay for additional carers for themselves or their family. Overall, five participants (19.23%) with either NMOSD or MOG paid for additional carers because of their condition. There were three participants (16.67%) with NMOSD, and two participants (25.00%) with MOG that paid for additional carers.

Cost of NMOSD

In the online questionnaire, participants estimated the amount they spend per month due to their condition, including doctors fees, transport, carers, health insurance gaps and complementary therapies. The most common amount spent by participants with NMOSD was between \$101 and \$249 (n=5, 27.78%). There were three participants who spent more than \$1000 a month (16.67%).

Burden of cost

As a follow up question, for participants who had monthly expenses due to their condition, participants were asked if the amount spent was a burden. The amount spent by participants with NMOSD was extremely significant or moderately significant burden for four participants (23.53%), somewhat significant for five participants (29.41%), and slightly or not at all significant for eight participants (47.06%)

Changes to employment status

Participants were asked, in the online questionnaire, if they had any changes to their employment status due to their condition. There were five participants with NMOSD that did not change their work status (27.78%), and two participants that were retired or not working when diagnosed (11.11%). Half of the participants with NMOSD quit their job (n=9, 50.00%), three (16.67%) accessed superannuation early, one participant (5.56%) took leave without pay, and one (5.56%) reduced the number of hours worked.

Changes to carer/partner employment status

Participants were asked, in the online questionnaire, if they had any changes to the employment status of their care or partner due to their condition. There were two (11.11%) participants with NMOSD without a main partner or carer. Most commonly, participants had partners or carers that did not change their work status due to the condition (n=7, 38.89%). There were two participants (11.11%) whose partner quit their job, two participants (11.11%) whose partners reduced the numbers of hours they worked. The partners of six participants (33.33%) took leave with pay, and two (11.11%) who took leave without pay.

Reduced income due to condition

Participants were then asked if they had a reduced family or household income due to their condition. As a follow up question, participants were asked if their family or household income had reduced due to condition. There were 10 participants (55.56%) with NMOSD that did not have a reduction in monthly income, and one participant that was not sure (5.56%). There were two participants (11.11%) that had a reduction between \$500 and \$1,999 per month, three participants (16.67%) that had a reduction between \$2,000 and \$5,000 a month, and two participants (11.11%) that had a loss of more than \$10,000 income per month.

Burden of reduced income

Participants were then asked if this reduced family or household income was a burden. The reduced income of participants with NMOSD was extremely significant or moderately significant burden for five (62.50%) participants, somewhat significant for two participants (25.00%), and not at all significant for one participant (12.50%)

Summary of medications

In the online questionnaire, participants answered a series of questions about their treatment, including treatment given, quality of life from treatment, side effects from treatment and how effective they thought the treatment was. Quality of life was rated on a scale of one to seven, where 1 is equal to “life was very distressing”, and 7 is equal to “life was great”. Effectiveness was rated on a scale of one to five, where one is equal to ineffective, and five is equal to very effective.

All participants with NMOSD had IV high dose steroids (n=18, 100.00%). There were two participants (11.11%) that did not have any side effects from this treatment, and the median quality of life was 2.00 (IQR=2.75), in the “Life was distressing” range. Participants with NMOSD rated this treatment as effective (median = 4.00, IQR = 1.00).

There were eight participants with NMOSD (44.44%) that had plasma exchange, two of these participants (25.00%) reported no side effects from this treatment. The median quality of life was 2.50 (IQR = 2.25), in the “life was a little distressing” to “life was distressing” range. On average, participants with NMOSD rated this treatment as to effective to very effective (median = 4.50, IQR = 1.00).

There were 11 participants with NMOSD (61.11%) that had prednisone, two of these participants (18.18%) reported no side effects from this treatment. The median quality of life was 2.00 (IQR = 2.50), in the “life was distressing” range. On average, participants with NMOSD rated this treatment as to effective (median = 4.00, IQR = 1.00)

There were 15 participants with NMOSD (83.33%) that had rituximab, seven of these participants (46.67%) reported no side effects from this treatment. The median quality of life was 4.00 (IQR = 1.00), in the “life was average” range. On average, participants with NMOSD rated this treatment as effective (median = 4.00, IQR = 1.00)

Allied health

Participants were asked about allied health services they used, the quality of life from these therapies, and how effective they found them. The most common allied health service used by participants with NMOSD was occupational therapy (n=10, 55.56%), followed by physiotherapy (n=9, 50.00%) and psychology (n=8, 44.44%).

The median quality of life from the most common allied health services was in the “life was a little distressing” range, occupational therapy (median=3.00, IQR=2.00), physiotherapy (median=3.00, IQR=2.00) and psychology (median=3.00, IQR=1.50). The average effectiveness from the most commonly used allied health services was in the moderately effective to effective range, occupational therapy (median = 3, IQR= 0.25), physiotherapy (median=4, IQR=2) and psychology (median = 3, IQR=1).

Lifestyle changes

Participants were asked about any lifestyle changes they had made since being diagnosed with their condition, the quality of life from these changes, and how effective they found them. Almost all participants (n=15, 83.33%) with NMOSD had made lifestyle changes to help manage their condition. The most common lifestyle change was exercise (n=13, 72.22%), followed by diet changes (n=7, 38.89%).

The median quality of life from the most common lifestyle changes was in the “life was average” range, exercise (median=4.00, IQR=2.00), and diet (median=4.00, IQR=2.00). The median effectiveness of exercise was in the somewhat effective range (median=200, IQR=2.00), and diet was in the effective range (median=4.00, IQR=1.00).

Complementary therapies

Participants were asked about complementary therapies they used, the quality of life from these therapies, and how effective they found them. Over 75% of participants with NMOSD used at least one type of complementary therapy (n=14, 77.78%). The most common complementary therapy used was mindfulness or relaxation techniques (n=10, 55.56%), followed by supplements (n=9, 50.00%), and massage therapy (n=6, 33.33%).

The average quality of life from the most common complementary therapies used was in the “life was average” range; mindfulness or relaxation techniques (median=4.0, IQR=2.50), supplements (median=4.0, IQR=2.00) and massage therapy (median=4.0, IQR=1.50). The average effectiveness from mindfulness or relaxation techniques was in the moderately effective to effective range (median=3.5, IQR=1.00), for supplements in the somewhat effective range (median=2.0, IQR=1.00) and for massage therapy in the moderately effective to effective range (median=3.5, IQR=1.75).

Clinical trials discussions

In the online questionnaire, participants were asked if they had discussions with their doctor about clinical trials, and if they did, who initiated the discussion. The majority of participants with NMOSD did not have any conversations about clinical trials with their doctor (n=15, 83.33%). The doctors of two participants (11.11%) brought up the topic, and one (5.56%) participant brought the topic with their doctor.

Clinical trial participation

As a follow up question, participants were asked if they had taken part in a clinical trial, and if they had not taken part if they were interested in taking part. No participants in this study had taken part in a clinical trial. The majority of participants with NMOSD were interested in taking part in a clinical trial (n=16, 88.89%), and two participants (11.11%) that were not interested in taking part in a clinical trial.

Description of mild side effects

In the structured interview, participants were asked how they would describe the term ‘mild side effects’. The most common description of ‘mild side effects’ was providing a specific example (n=14, 77.78%), followed by those that can be self-managed and do not interfere with everyday life (n=5, (27.78%).

Description of mild side effects: Specific side effects

There were five participants (27.78%) that described ‘mild side effects’ by giving the example of numbness/paresthesia and five participants (27.78%) who gave the example of neuropathic pain to describe mild side effects.

Description of severe side effects

In the structured interview, participants were asked how they would describe the term ‘severe side effects’. The most common description of ‘severe side effects’ was providing a specific example to describe severe side effects (n=13, 72.22%).

Description of severe side effects: Specific side effects

The most common specific side effect given to describe ‘severe side effects’ was pain (n=6, 33.33%).

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common theme described was adhering to treatment as long as side effects are tolerable (n=5, 27.78%).

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common response from six participants (33.33%) was needing to see a reduction in the symptoms of their condition. This was followed by needing to experience an improvement in pain levels (n=5, 27.78%).

Preference for treatment

Participants were asked to describe whether they would prefer treatment at home or in hospital. The most common response from nine participants (50.00%) was a preference for treatment at home. This was followed by a preference for treatment in hospital (n=5, 27.78%).

Preference for treatment: Rationale

There were eight participants (44.44%) who described preferring to have treatment at home because it is more convenient/comfortable and less interruption to daily life.

Support needed for treatment at home

Participants were asked what support they would need to ease their anxiety about having treatment at home. There were three participants (16.67%) who described needing to be checked regularly by GP/Nurse at home.

Access to telehealth or remote access

Participants were asked whether they have access to telehealth or remote access. There were nine participants (55.56%) who described not having access to telehealth or remote access and eight participants (38.89%) described having access to telehealth or remote access.

Access to telehealth or remote access: Experience

There were nine participants (55.56%) who did not receive care through telehealth or remote access and so gave no opinion. This was followed by five participants (22.22%) who were pleased with their experience of telehealth or remote access.

What would it mean if treatment worked

Participants were asked what it would mean for them if treatment worked. The most common response from six participants (33.33%) was allowing them to engage more with social activities and family life.

Main provider of treatment

Participants were asked in the online questionnaire who was the main healthcare professional that provided treatment and management of their condition.

All participants had a neurologist as their main healthcare professional (n=26, 100.00%).

Access to healthcare professionals

Participants noted in the online questionnaire the healthcare professionals they had access to for the treatment and management of their condition (Table 5.1, Figure 5.1).

NMOSD

All participants with NMOSD had a neurologist for their condition. Over half of the participants had an

ophthalmologist (n=10, 55.56%), general practitioner (n=10, 55.56%), and occupational therapist (n=10, 55.56%) to treat or manage their condition.

MOG

All participants with MOG had a neurologist, and an ophthalmologist for their condition. Half of the participants had a physiotherapist (n=4, 50.00%), and a general practitioner (n=4, 50.00%) to treat or manage their condition.

NMOSD or MOG

Overall, all participants with NMOSD or MOG had a neurologist for their condition (n=26, 100%). Over half of the participants had an ophthalmologist (n=18, 69.23%), and a general practitioner (n=14, 53.85%) to treat or manage their condition.

Table 5.1: Access to healthcare professionals

Healthcare professional	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Neurologist	18	100.00	8	100.00	26	100.00
Ophthalmologist	10	55.56	8	100.00	18	69.23
Physical Medicine and Rehabilitation doctor	2	11.11	1	12.50	3	11.54
Urologist	5	27.78	0	0.00	5	19.23
Pain specialist	3	16.67	0	0.00	3	11.54
General Practitioner (GP)	10	55.56	4	50.00	14	53.85
Speech pathologist	2	11.11	0	0.00	2	7.69
Physiotherapist	9	50.00	4	50.00	13	50.00
Occupational therapist	10	55.56	1	12.50	11	42.31
Exercise physiologist	2	11.11	0	0.00	2	7.69
Psychologist	8	44.44	2	25.00	10	38.46
Counsellor	1	5.56	0	0.00	1	3.85
Neuropsychologist	1	5.56	0	0.00	1	3.85
Osteopath	3	16.67	1	12.50	4	15.38
Chiropractor	1	5.56	1	12.50	2	7.69
Dietitian	2	11.11	1	12.50	3	11.54
Social worker	4	22.22	0	0.00	4	15.38
NMOSD care coordinator	1	5.56	0	0.00	1	3.85
Pharmacist	4	22.22	2	25.00	6	23.08
Other	4	22.22	1	12.50	5	19.23

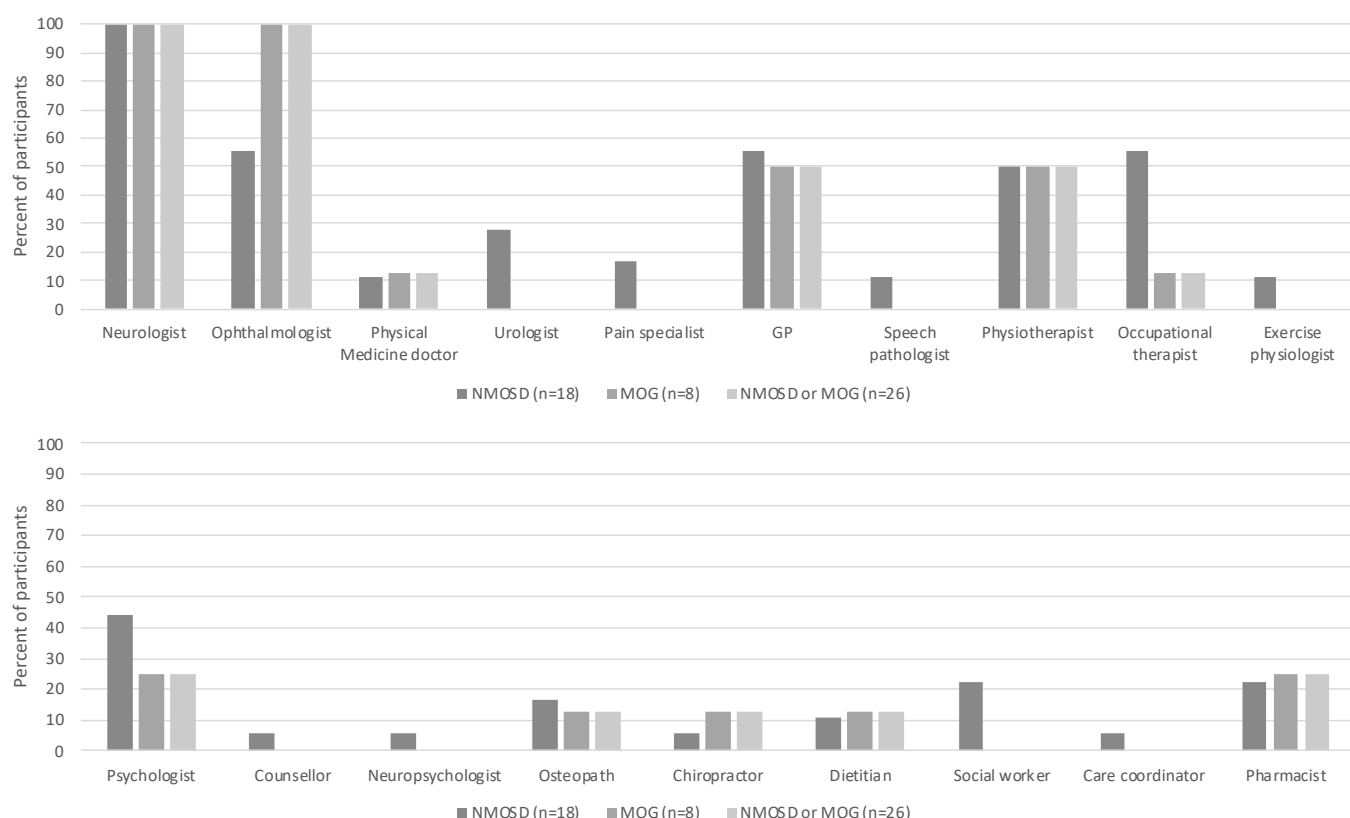


Figure 5.1: Access to healthcare professionals

Respect shown

Participants were asked to think about how respectfully they were treated throughout their experience, this question was asked in the online questionnaire (Table 5.2, Figure 5.2).

NMOSD

The majority of participants with NMOSD indicated that they had been treated with respect throughout their experience, with the exception of one or two occasions (n=13, 72.22%), two participants (11.11%) felt they had been treated with respect, and three participants (16.67%) felt they had not been treated respectfully.

MOG

The majority of participants with MOG felt they had been treated with respect through-out their treatment (n=5, 62.50%), and three participants (37.50%) that felt they had been treated with respect with the exception of one or two occasions. Zero participants with MOG felt they had not been treated with respect.

NMOSD or MOG

Overall, the majority of participants with NMOSD or MOG indicated that they had been treated with respect throughout their experience, with the exception of one or two occasions (n=16, 61.54%), seven participants (26.92%) felt they had been treated with respect, and three participants (11.54%) felt they had not been treated respectfully.

Table 5.2: Respect shown

Respect shown	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Respect shown	2	11.11	5	62.50	7	26.92
Respect shown, with the exception of one or two occasions	13	72.22	3	37.50	16	61.54
Respect not shown	3	16.67	0	0.00	3	11.54

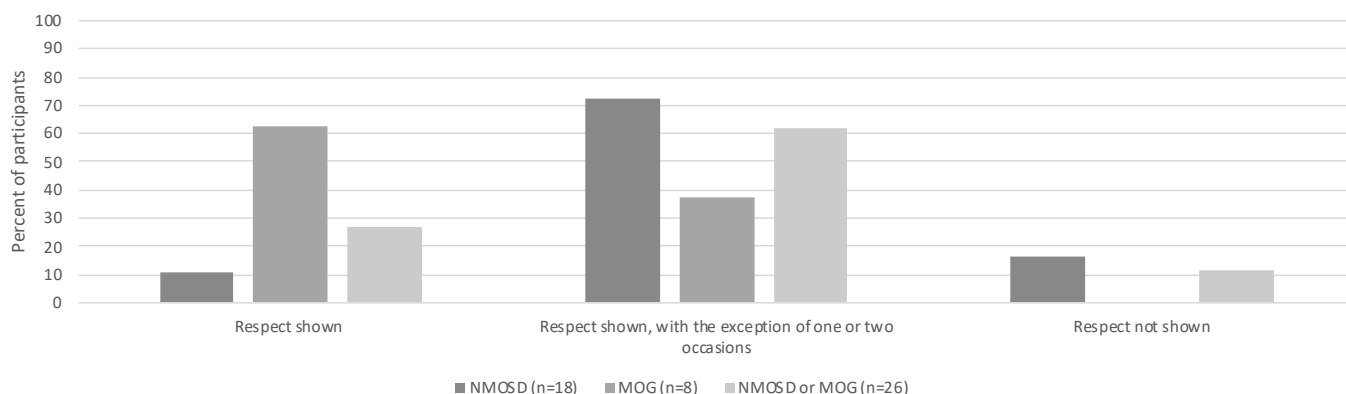


Figure 5.2: Respect shown

Health care system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient (Table 5.3, Figures 5.3 to 5.5).

NMOSD

The majority of participants with NMOSD had health insurance (n=11, 61.11%), and the same number were asked if they wanted to be treated as a public or private patient. There were 12 participants (66.67%) that were asked if they had private health insurance.

Most participants with NMOSD were treated as a public patient (n=12, 66.67%), there were five participants (27.78%) treated equally as a public and private patient, and one participant (5.56%) mostly as a private patient.

Most participants with NMOSD were treated in the public healthcare system (n=14, 77.78%), there were three participants (16.67%) treated equally in the public and private system, and one participant (5.56%) mostly in the private system.

MOG

The majority of participants with MOG had health insurance (n=6, 75.00%). There were seven participants (87.50%) asked if they wanted to be

treated as a public or private patient, and the same number were asked if they had private health insurance.

Half of participants with MOG were treated as a public patient (n=4, 50.00%), and half as private patients (n=4, 50.00%). Most participants were treated in the public system (n=6, 33.33%).

Most participants with MOG were treated in the public healthcare system (n=6, 75.00%), and two participants (25.00%) mostly in the private system.

NMOSD or MOG

Overall, the participants with NMOSD or MOG mostly had health insurance (n=17, 65.38%). There were 18 participants (69.23%) that were asked if they wanted to be treated as a public or private patient, and 19 participants (73.08%) that were asked if they had private health insurance.

The majority of participants were treated as a public patient (n=16, 61.54%), five participants (19.23%) were treated as private patients, and five participants (19.23%) were treated equally as public and private patients.

Most participants were treated in the public health system (n=20, 76.92%), three participants (11.54%) were mostly treated in the private health system, and three participants (11.54%) treated equally in the public and private health system.

Table 5.3: Health care system

Health care services	Response	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
		Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Private health insurance	No	7	38.89	2	25.00	9	34.62
	Yes	11	61.11	6	75.00	17	65.38
Asked to be treated as a public or private patient	No	7	38.89	1	12.50	8	30.77
	Yes	11	61.11	7	87.50	18	69.23
Asked about private health insurance status	No	6	33.33	1	12.50	7	26.92
	Yes	12	66.67	7	87.50	19	73.08
Mostly treated as a public or a private patient	Equally as a public and private patient	5	27.78	0	0.00	5	19.23
	Private patient	1	5.56	4	50.00	5	19.23
	Public patient	12	66.67	4	50.00	16	61.54
Hospital system primarily been treated in	Both public and private	3	16.67	0	0.00	3	11.54
	Private	1	5.56	2	25.00	3	11.54
	Public	14	77.78	6	75.00	20	76.92

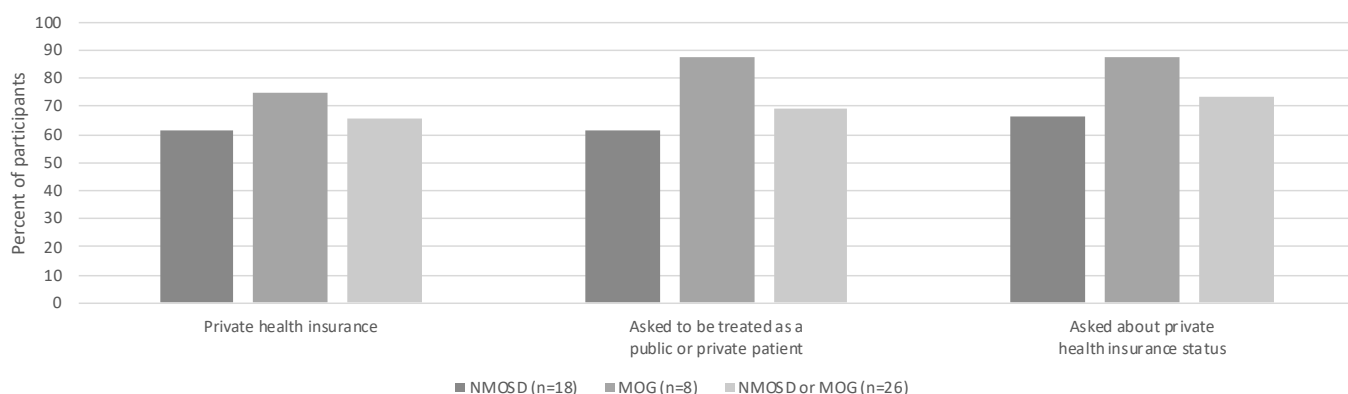


Figure 5.3: Private health insurance

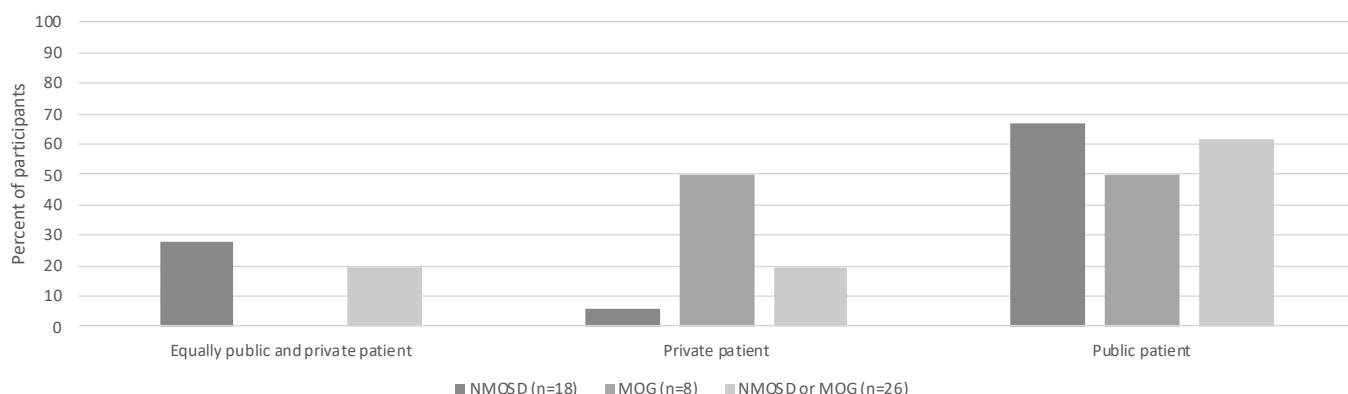


Figure 5.4: Public/private patient

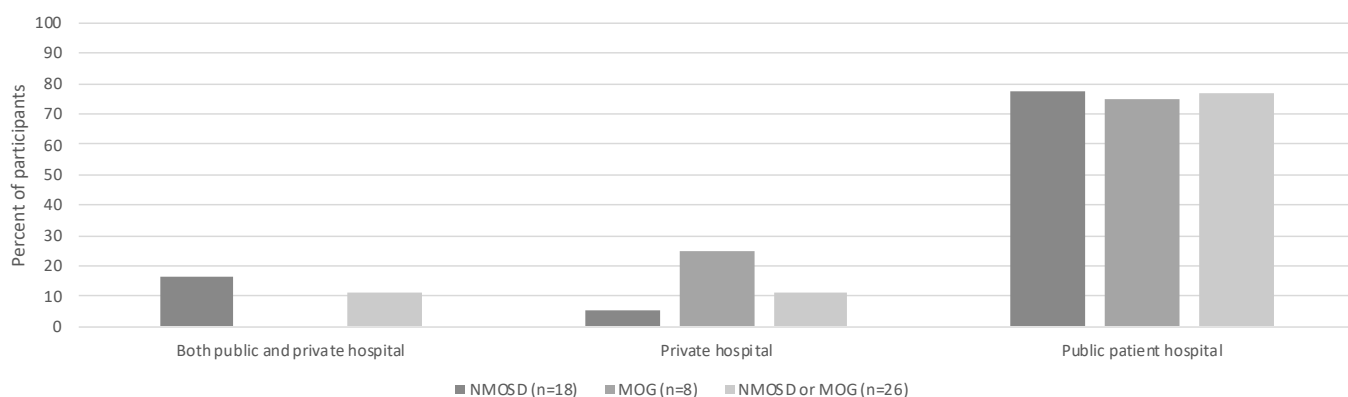


Figure 5.5: Public/private health system

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire. The first question was about having to delay or cancel healthcare appointments because

they were unable to afford them. There were no participants that often or very often had to cancel appointments due to affordability (Table 5.4, Figure 5.6).

NMOSD

The majority of participants with NMOSD never or rarely cancelled their appointments due to cost (n=12, 66.67%), and six participants (33.33%) sometimes had to delay or cancel appointments due to affordability.

MOG

All participants with MOG had never cancelled appointments due to affordability.

NMOSD or MOG

Overall, the majority of participants with NMOSD or MOG never or rarely cancelled their appointments due to cost (n=20, 76.93%), and six participants (23.08%) sometimes had to delay or cancel appointments due to affordability.

Table 5.4: Healthcare appointments

Delay or cancel healthcare appointments due to affordability	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Never	11	61.11	8	100.00	19	73.08
Rarely	1	5.56	0	0.00	1	3.85
Sometimes	6	33.33	0	0.00	6	23.08
Often	0	0.00	0	0.00	0	0.00
Very often	0	0.00	0	0.00	0	0.00

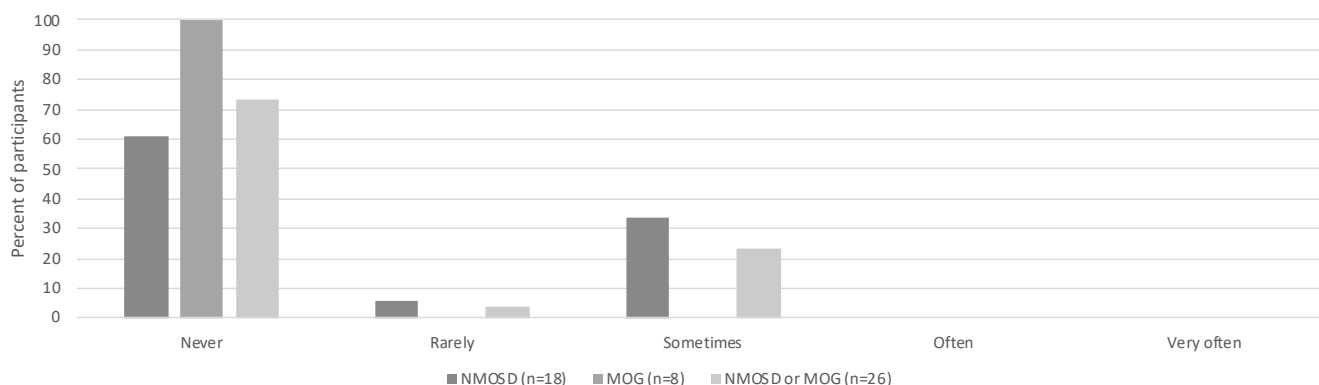


Figure 5.6: Healthcare appointments

Filling prescriptions

Participants were then asked if they were unable to fill prescriptions for essential medicines due to cost. There were no participants that often or very often were unable to fill prescriptions due to affordability (Table 5.5, Figure 5.7).

MOG

All participants with MOG had never had trouble filling prescriptions due to cost.

NMOSD or MOG

Overall, the majority of participants with NMOSD or MOG never or rarely could not fill prescriptions due to cost (n=24, 92.31%), and two participants (7.69%) sometimes could not fill prescriptions due to cost.

NMOSD

The majority of participants with NMOSD never or rarely could not fill prescriptions due to cost (n=16, 88.89%), and two participants (11.11%) sometimes could not fill prescriptions due to cost.

Table 5.5: Filling prescriptions

Did not fill prescriptions due to cost	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Never	14	77.78	8	100.00	22	84.62
Rarely	2	11.11	0	0.00	2	7.69
Sometimes	2	11.11	0	0.00	2	7.69
Often	0	0.00	0	0.00	0	0.00
Very often	0	0.00	0	0.00	0	0.00

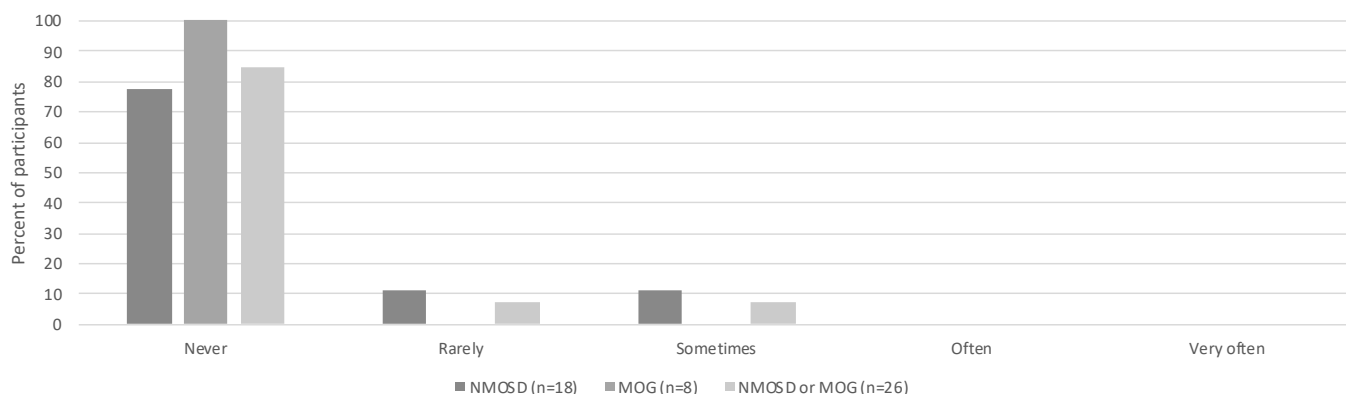


Figure 5.7: Filling prescriptions

Paying for basic essentials

Participants were asked as a result of their condition, if it made it difficult to pay for basic necessities such as housing, food and electricity. There were no participants that very often had trouble paying for basic essentials (Table 5.6, Figure 5.8).

NMOSD

The majority of participants with NMOSD never or rarely had trouble paying for basic essentials (n=12, 66.66%), and six participants (33.33%) sometimes or often had trouble paying for basic essentials.

MOG

All participants with MOG had never or rarely had trouble paying for basic essentials.

NMOSD or MOG

The majority of participants with NMOSD or MOG never or rarely had trouble paying for basic essentials (n=20, 76.92%), and six participants (23.08%) sometimes or often had trouble paying for basic essentials.

Table 5.6: Paying for basic essentials

Difficult to pay for basic essentials	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Never	6	33.33	7	87.50	13	50.00
Rarely	6	33.33	1	12.50	7	26.92
Sometimes	5	27.78	0	0.00	5	19.23
Often	1	5.56	0	0.00	1	3.85
Very often	0	0.00	0	0.00	0	0.00

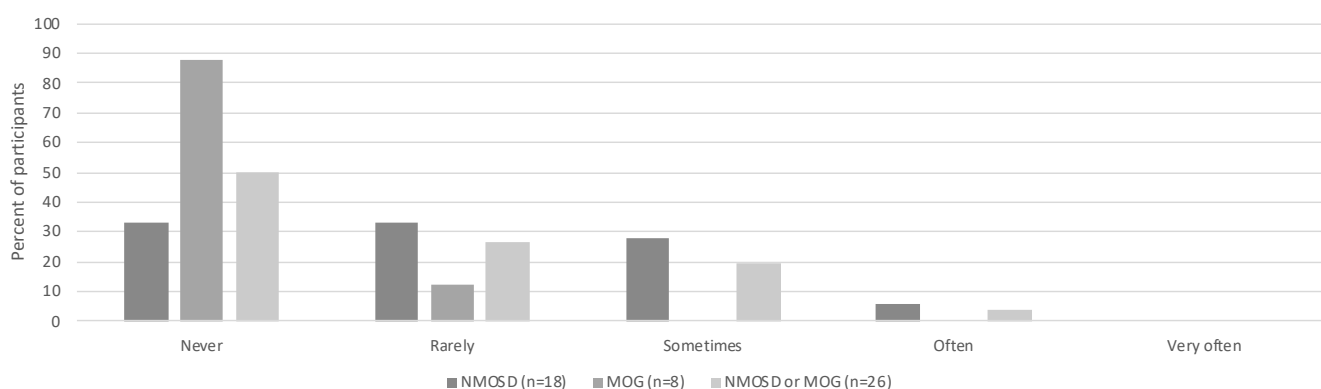


Figure 5.8: Paying for basic essentials

Pay for additional carers

Participants were then asked if as a result of their condition, if they had to pay for additional carers for themselves or their family (Table 5.7, Figure 5.9).

Overall, five participants (19.23%) with either NMOSD or MOG paid for additional carers because of their condition. There were three participants (16.67%) with NMOSD, and two participants (25.00%) with MOG that paid for additional carers.

Table 5.7: Pay for additional carers

Pay for additional carers for self or family	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
No	15	83.33	6	75.00	21	80.77
Yes	3	16.67	2	25.00	5	19.23

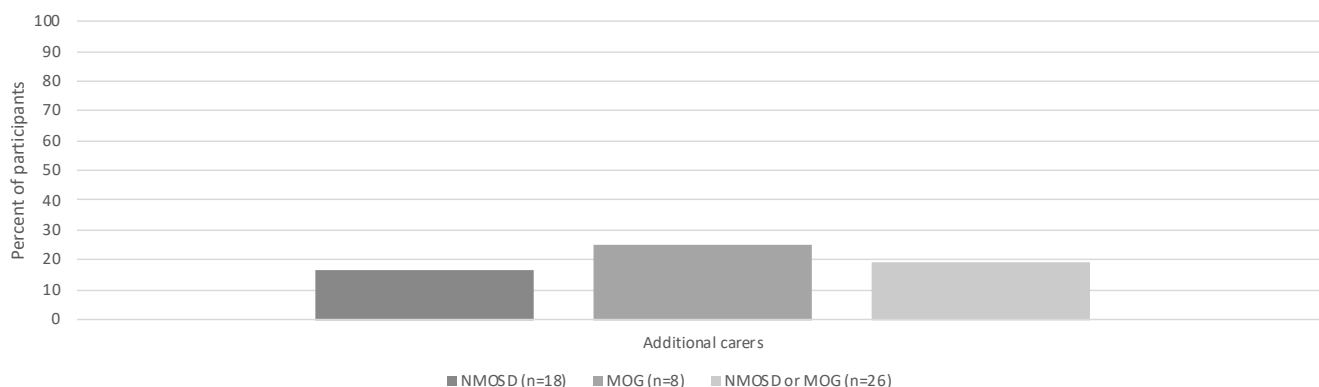


Figure 5.9: Pay for additional carers

Cost of NMOSD or MOG

In the online questionnaire, participants estimated the amount they spend per month due to their condition, including doctors fees, transport, carers, health insurance gaps and complementary therapies. Where the response was given in a dollar amount, it is listed in the table below (Table 5.8, Figure 5.10).

NMOSD

The most common amount spent by participants with NMOSD was between \$101 and \$249 (n=5, 27.78%). There were three participants who spent more than \$1000 a month (16.67%).

MOG

The most common amount spent by participants with MOG was between \$101 and \$249 (n=3, 37.50%). There were no participants who spent more than \$1000 a month.

NMOSD or MOG

The most common amount spent by participants with NMOSD or MOG was between \$101 and \$249 (n=8, 30.77%). There were three participants who spent more than \$1000 a month (11.54%)

Table 5.8: Estimated monthly out of pocket expenses due to condition

Estimated monthly out of pocket expenses	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
\$0	1	5.56	1	12.50	2	7.69
Less than \$100	2	11.11	0	0.00	2	7.69
\$100 to \$249	5	27.78	3	37.50	8	30.77
\$250 to \$499	3	16.67	2	25.00	5	19.23
\$500 to \$999	3	16.67	1	12.50	4	15.38
\$1000 or more	3	16.67	0	0.00	3	11.54
Not sure	1	5.56	1	12.50	2	7.69

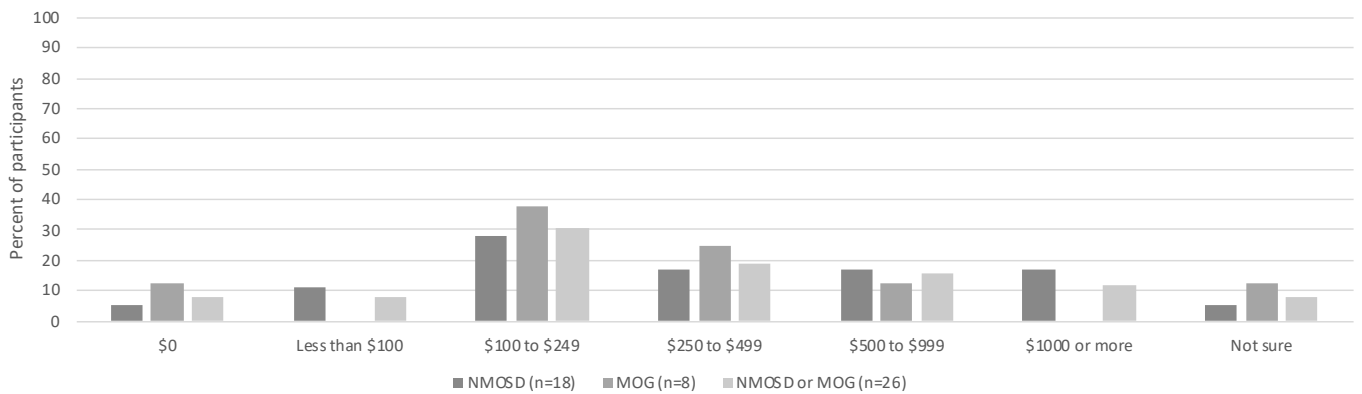


Table 5.10: Estimated monthly out of pocket expenses due to condition

Burden of cost

As a follow up question, for participants who had monthly expenses due to their condition, participants were asked if the amount spent was a burden (Table 5.9, Figure 5.11).

The amount spent by participants with MOG was extremely significant for one participant (14.29%), somewhat significant for two participants (28.57%), and slightly or not at all significant for four participants (57.14%)

NMOSD

The amount spent by participants with NMOSD was extremely significant or moderately significant burden for four participants (23.53%), somewhat significant for five participants (29.41%), and slightly or not at all significant for eight participants (47.06%)

NMOSD or MOG

Overall, the amount spent by participants with NMOSD or MOG was extremely significant or moderately significant burden for five participants (20.83%), somewhat significant for seven participants (29.17%), and slightly or not at all significant for 12 participants (50.00%)

MOG

Table 5.9: Burden of cost

Burden of out of pocket expenses	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=17)	Percent	Number (n=7)	Percent	Number (n=24)	Percent
Extremely significant	1	5.88	1	14.29	2	8.33
Moderately significant	3	17.65	0	0.00	3	12.50
Somewhat significant	5	29.41	2	28.57	7	29.17
Slightly significant	4	23.53	2	28.57	6	25.00
Not at all significant	4	23.53	2	28.57	6	25.00

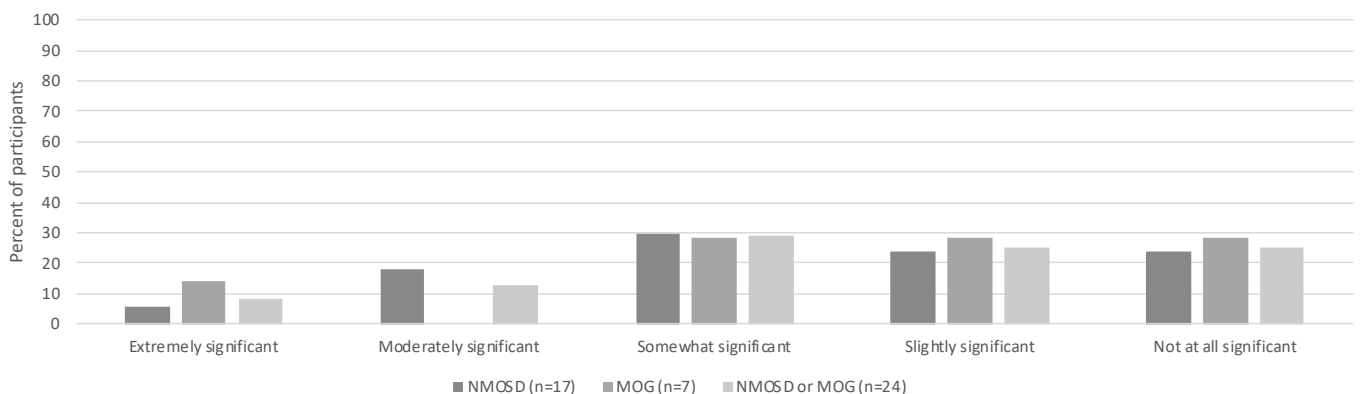


Figure 5.11: Burden of cost

Changes to employment status

Participants were asked, in the online questionnaire, if they had any changes to their employment status due to their condition. Participants were able to choose multiple changes to employment (Table 5.10, Figure 5.12).

NMOSD

There were five participants with NMOSD that did not change their work status (27.78%), and two participants that were retired or not working when diagnosed (11.11%). Half of the participants with NMOSD quit their job (n=9, 50.00%), three (16.67%) accessed superannuation early, one participant (5.56%) took leave without pay, and one (5.56%) reduced the number of hours worked.

MOG

All participants with MOG had made some form of changes to their work status. There were two

participants (25.00%) with MOG and that were retired or not working when diagnosed. There were three participants (37.50%) that took leave without pay, and one participant (12.50) that took leave with pay. Two participants (25.00%) reduced the number of hours worked, and one participant (12.50) quit their job.

NMOSD and MOG

Overall, for participants with NMOSD or MOG, there were five participants with NMOSD that did not change their work status (19.23%), and four participants that were retired or not working when diagnosed (15.38%). There were 10 participants (38.46%) that quit their job, three participants (11.54%) accessed superannuation early, four participants (15.38%) took leave without pay, one participant (3.85%) took leave without pay, and three participants (11.54%) reduced the number of hours worked.

Table 5.10: Changes to employment status

Changes in work status due to condition	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Work status has not changed	5	27.78	0	0.00	5	19.23
Retired or did not have a job	2	11.11	2	25.00	4	15.38
Had to quit job	9	50.00	1	12.50	10	38.46
Reduced number of hours worked	1	5.56	2	25.00	3	11.54
Leave from work without pay	1	5.56	3	37.50	4	15.38
Leave from work with pay	0	0.00	1	12.50	1	3.85
Accessed Superannuation early due to condition	3	16.67	0	0.00	3	11.54

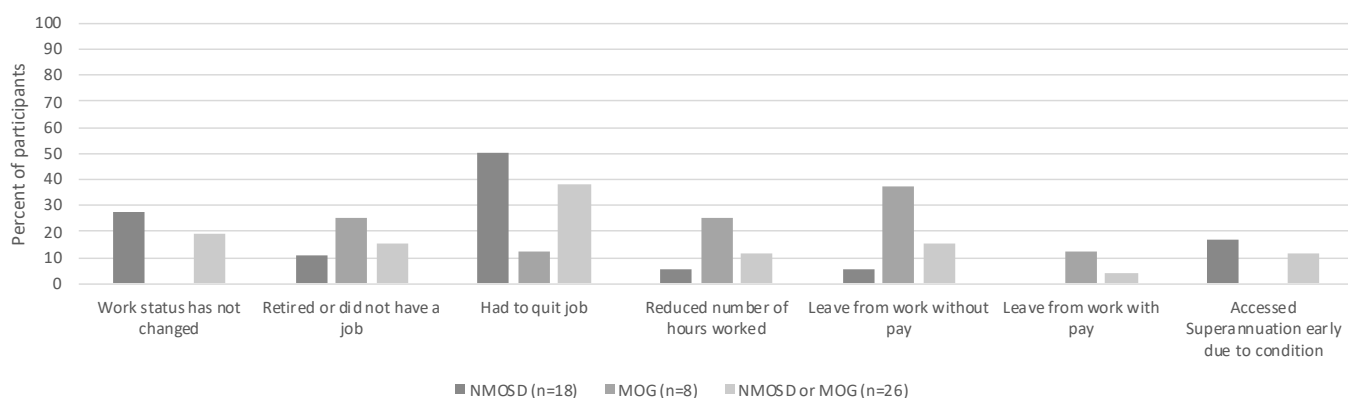


Figure 5.12: Changes to employment status

Changes to carer/partner employment status

Participants were asked, in the online questionnaire, if they had any changes to the employment status of their care or partner due to their condition. Participants were able to choose multiple changes to employment (Table 5.11, Figure 5.13).

NMOSD

There were two (11.11%) participants with NMOSD without a main partner or carer. Most commonly, participants had partners or carers that did not change their work status due to the condition (n=7, 38.89%). There were two participants (11.11%) whose partner quit their job, two participants (11.11%) whose partners reduced the numbers of hours they worked. The partners of six participants (33.33%) took leave with pay, and two (11.11%) who took leave without pay.

MOG

There was one (12.50%) participant with MOG without a main partner or carer. Most commonly, participants had partners or carers that did not change their work status due to the condition (n=4, 50%).

NMOSD or MOG

Overall, for participants with NMOSD or MOG, there were three (11.54%) participants without a main

partner or carer. Most commonly, participants had partners or carers that did not change their work status due to the condition (n=11, 42.31%). There were two participants (7.69%) whose partner quit their job, two participants (7.69%) whose partners reduced the numbers of hours they worked. The partners of seven participants (26.92%) took leave with pay, and two (7.69%) who took leave without pay.

Table 5.11: Changes to care/partner employment status

Changes to care/partner employment status	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Does not have a partner/main carer	2	11.11	1	12.50	3	11.54
Retired or did not have a job	1	5.56	3	37.50	4	15.38
Work status has not changed	7	38.89	4	50.00	11	42.31
Had to quit job	2	11.11	0	0.00	2	7.69
Reduced number of hours worked	2	11.11	0	0.00	2	7.69
Leave from work without pay	2	11.11	0	0.00	2	7.69
Leave from work with pay	6	33.33	1	12.50	7	26.92

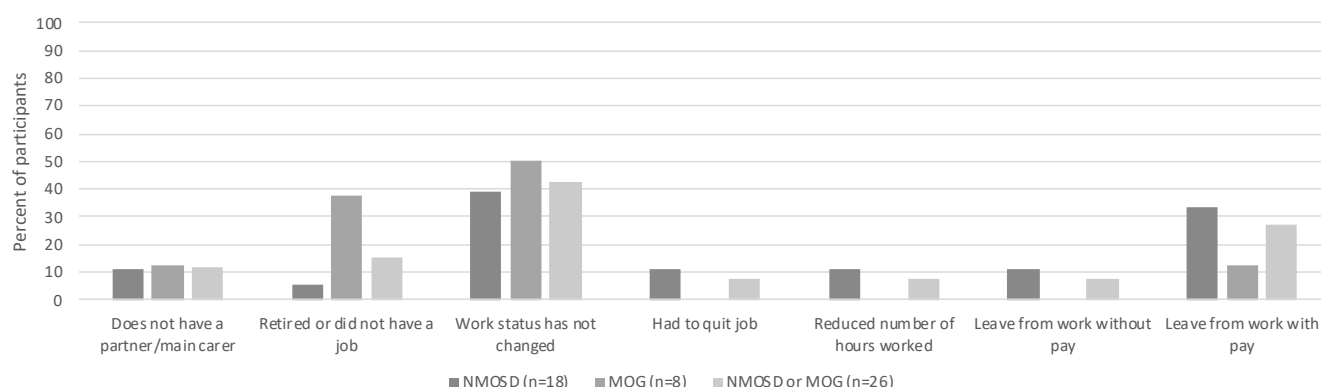


Figure 5.13: Changes to care/partner employment status

Reduced income due to condition

Participants were then asked if they had a reduced family or household income due to their condition. As a follow up question, participants were asked if their family or household income had reduced due to condition. Where a dollar amount was given, it is listed in the table below (Table 5.12, Figure 5.14).

NMOSD

There were 10 participants (55.56%) with NMOSD that did not have a reduction in monthly income, and one participant that was not sure (5.56%). There were two participants (11.11%) that had a reduction between \$500 and \$1,999 per month, three participants (16.67%) that had a reduction between \$2,000 and \$5,000 a month, and two participants (11.11%) that had a loss of more than \$10,000 income per month.

MOG

There were four participants (50.00%) with MOG that did not have a reduction in monthly income. There were two participants (25.00%) that had a reduction between \$500 and \$1,999 per month, and two participants (25.00%) that had a reduction between \$2,000 and \$5,000 a month.

NMOSD or MOG

Overall, for participants with NMOSD or MOG there were 14 participants (53.85%) that did not have a reduction in monthly income, and one participant that was not sure (3.85%). There were four participants (15.38%) that had a reduction between \$500 and \$1,999 per month, five participants (19.23%) that had a reduction between \$2,000 and \$5,000 a month, and two participants (7.69%) that had a loss of more than \$10,000 income per month.

Table 5.12: Estimated monthly loss of income

Estimated monthly loss of income	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
\$0	10	55.56	4	50.00	14	53.85
\$500 to \$1999	2	11.11	2	25.00	4	15.38
\$2000 to \$5000	3	16.67	2	25.00	5	19.23
More than \$10,000	2	11.11	0	0.00	2	7.69
Not sure	1	5.56	0	0.00	1	3.85

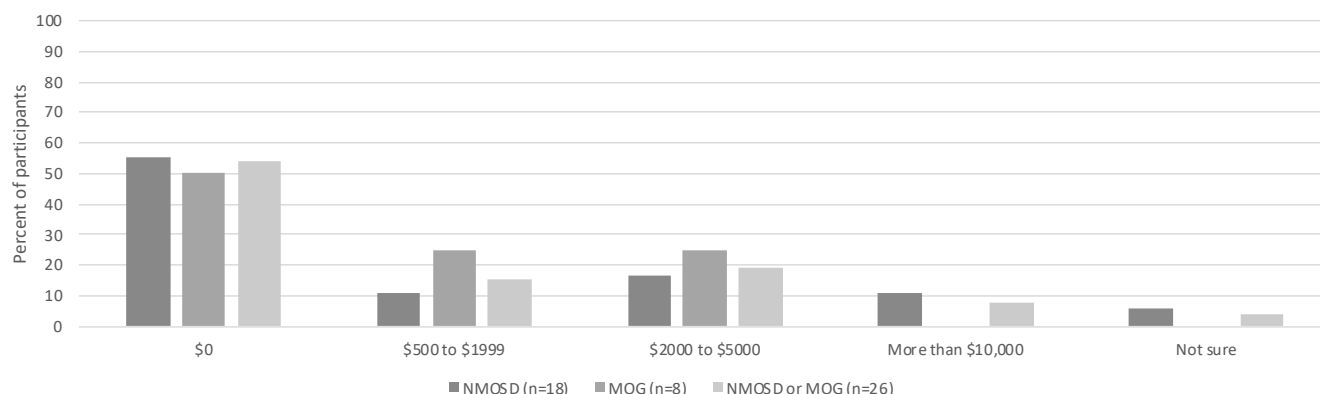


Figure 5.14: Estimated monthly loss of income

Burden of reduced income

Participants were then asked if this reduced family or household income was a burden (Table 5.13, Figure 5.15).

NMOSD

The reduced income of participants with NMOSD was extremely significant or moderately significant burden for five (62.50%) participants, somewhat significant for two participants (25.00%), and not at all significant for one participant (12.50%).

MOG

The reduced income of participants with MOG was moderately significant for one (25.00%) participant, somewhat significant for one participant (25.00%), and slightly significant for two participants (50.00%).

NMOSD or MOG

Overall, the reduced income of participants with NMOSD or MOG was extremely significant or moderately significant burden for six (50.00%) participants, somewhat significant for three participants (25.00%), and slightly or not at all significant for three participants (25.00%).

Table 5.13: Burden of reduced income

Burden of reduced income	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=8)	Percent	Number (n=4)	Percent	Number (n=12)	Percent
Extremely significant	2	25.00	0	0.00	2	16.67
Moderately significant	3	37.50	1	25.00	4	33.33
Somewhat significant	2	25.00	1	25.00	3	25.00
Slightly significant	0	0.00	2	50.00	2	16.67
Not at all significant	1	12.50	0	0.00	1	8.33

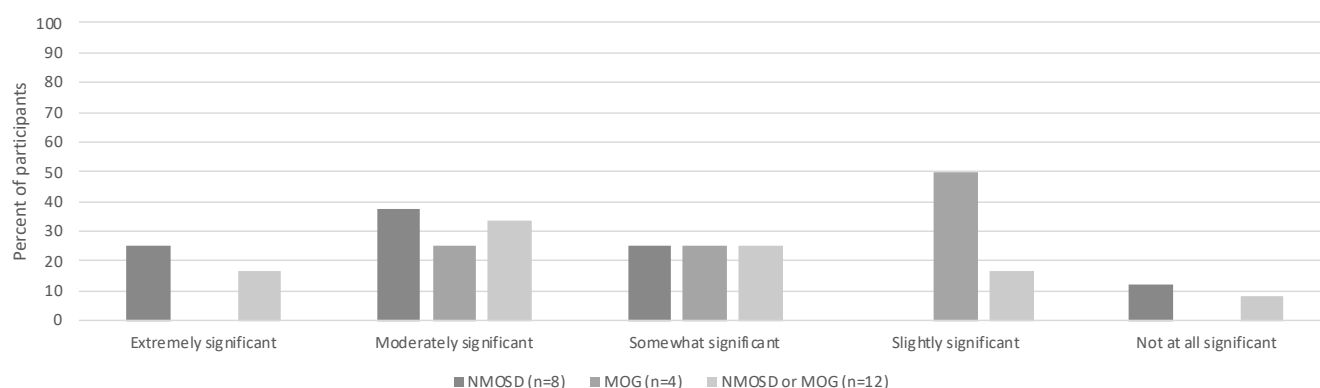


Figure 5.15: Burden of reduced income

Summary of medications

In the online questionnaire, participants answered a series of questions about their treatment, including treatment given, quality of life from treatment, side effects from treatment and how effective they thought the treatment was.

Quality of life was rated on a scale of one to seven, where 1 is equal to “life was very distressing”, and 7 is equal to “life was great”.

Effectiveness was rated on a scale of one to five, where one is equal to ineffective, and five is equal to very effective.

The treatments used by participants in this study are listed in Table 5.14 (Figure 5.16), the number of participants with side effects in Table 5.15, Figure 5.17, when five or more participants have taken treatment the average quality of life (Table 5.16, Figure 5.18), and effectiveness (Table 5.17, Figure 5.19) and when more than 10 participants took a particular treatment, details about quality of life, side effects, and effectiveness are given in Tables 5.18 to 5.21). The most common treatments used were IV high dose steroids, rituximab, prednisone, and PLEX.

NMOSD

All participants with NMOSD had IV high dose steroids (n=18, 100.00%). There were two participants (11.11%) that did not have any side effects from this treatment, and the median quality of life was 2.00 (IQR=2.75), in the “Life was distressing” range. Participants with NMOSD rated this treatment as effective (median = 4.00, IQR = 1.00)

There were eight participants with NMOSD (44.44%) that had plasma exchange, two of these participants (25.00%) reported no side effects from this treatment. The median quality of life was 2.50 (IQR = 2.25), in the “life was a little distressing” to “life was distressing” range. On average, participants with NMOSD rated this treatment as to effective to very effective (median = 4.50, IQR = 1.00).

There were 11 participants with NMOSD (61.11%) that had prednisone, two of these participants (18.18%) reported no side effects from this treatment. The median quality of life was 2.00 (IQR = 2.50), in the “life was distressing” range. On

average, participants with NMOSD rated this treatment as to effective (median = 4.00, IQR = 1.00)

There were 15 participants with NMOSD (83.33%) that had rituximab, seven of these participants (46.67%) reported no side effects from this treatment. The median quality of life was 4.00 (IQR = 1.00), in the “life was average” range. On average, participants with NMOSD rated this treatment as effective (median = 4.00, IQR = 1.00)

MOG

All participants with MOG had IV high dose steroids (n=8, 100.00%), all had side effects from this treatment. The median quality of life was 3.00 (IQR=1.00), in the “Life was a little distressing” range. Participants with MOG rated this treatment as effective to very effective (median = 4.50, IQR = 1.00)

All participants with MOG had that had prednisone (n=8, 100.00%), all had side effects from this treatment. The median quality of life was 3.50 (IQR = 1.25), in the “life was a little distressing” to “life was average” range. On average, participants with MOG rated this treatment as moderately effective to effective (median = 3.50, IQR = 2.25).

NMOSD or MOG

Overall, participants with NMOSD or MOG were all treated with IV high dose steroids (n=26, 100.00%). There were two participants (7.69%) that did not have any side effects from this treatment, and the median quality of life was 2.00 (IQR=2.00), in the “Life was distressing” range. Participants with NMOSD or MOG rated this treatment as effective (median = 4.00, IQR = 1.00)

There were 10 participants with NMOSD or MOG (38.46%) that had plasma exchange, three of these participants (30.00%) reported no side effects from this treatment. The median quality of life was 2.00 (IQR = 1.75), in the “life was distressing” range. On average, participants with NMOSD or MOG rated this treatment as to effective (median = 4.00, IQR = 1.75).

There were 19 participants with NMOSD or MOG (73.08%) that had prednisone, two of these participants (10.53%) reported no side effects from this treatment. The median quality of life was 3.00 (IQR = 2.00), in the “life was a little distressing”

range. On average, participants with NMOSD or MOG rated this treatment as to effective (median = 4.00, IQR = 2.00)

There were 20 participants with NMOSD or MOG (76.92%) that had rituximab, eight of these participants (40.00%) reported no side effects from

this treatment. The median quality of life was 3.50 (IQR = 1.25), in the “life was a little distressing” to “life was average” range. On average, participants with NMOSD rated this treatment as effective (median = 4.00, IQR = 2.00)

Table 5.14: Summary of treatments

Treatment	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
IV High dose steroids	18	100.00	8	100.00	26	100.00
Plasma exchange (PLEX)	8	44.44	2	25.00	10	38.46
Prednisone	11	61.11	8	100.00	19	73.08
Azathioprine	4	22.22	0	0.00	4	15.38
Mycophenolate mofetil, MMF	5	27.78	1	12.50	6	23.08
Rituximab	15	83.33	5	62.50	20	76.92
Methotrexate	2	11.11	0	0.00	2	7.69
Ecilizumab	0	0.00	0	0.00	0	0.00
Tocilizumab	2	11.11	0	0.00	2	7.69
Inebilizumab	0	0.00	0	0.00	0	0.00
Satralizumab	0	0.00	0	0.00	0	0.00

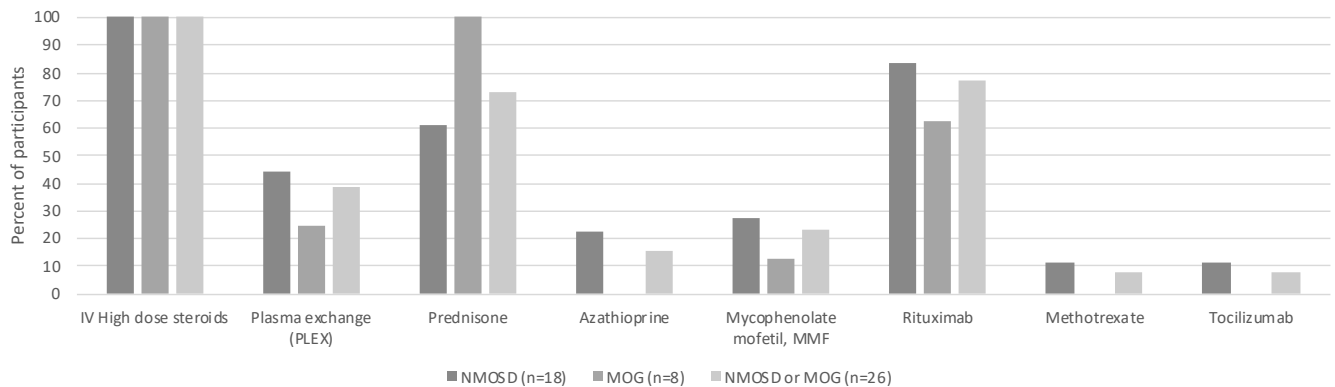


Figure 5.16: Summary of treatments

IV high dose steroids	PLEX	Rituximab	Prednisone	Azathioprine	MMF	Methotrexate	Tocilizumab	IVIG
IV high dose steroids		Rituximab	Prednisone	Azathioprine	MMF	Methotrexate	Tocilizumab	
IV high dose steroids	PLEX	Rituximab	Prednisone	Azathioprine	MMF	Methotrexate		
IV high dose steroids	PLEX	Rituximab	Prednisone		MMF			
IV high dose steroids	PLEX	Rituximab	Prednisone		MMF			
IV high dose steroids		Rituximab	Prednisone					
IV high dose steroids		Rituximab	Prednisone					
IV high dose steroids		Rituximab	Prednisone					
IV high dose steroids	PLEX	Rituximab						
IV high dose steroids	PLEX	Rituximab						
IV high dose steroids	PLEX	Rituximab						
IV high dose steroids		Rituximab		Azathioprine			Tocilizumab	
IV high dose steroids		Rituximab						
IV high dose steroids		Rituximab						
IV high dose steroids		Rituximab						IVIG
IV high dose steroids			Prednisone					
IV high dose steroids			Prednisone	Azathioprine	MMF			
IV high dose steroids			Prednisone					

Table Key

As needed/PRN administration	Treatment had stopped at time of this study	Treatment was ongoing at time of this study
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Figure 5.16b: Summary of treatments experienced by participants with NMOSD (n=18)

Table 5.15 : Number of participants without side effects from treatment

Treatment	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number	Percent	Number	Percent	Number	Percent
IV High dose steroids (NMO=18, MNO=8)	2	11.11	0	0.00	2	7.69
Plasma exchange (NMO=8, MOG= 2)	2	25.00	1	50.00	3	30.00
Prednisone (NMO=11, MOG=8)	2	18.18	0	0.00	2	10.53
Azathioprine (NMO=4, MOG=0)	0	0.00	NA	NA	0	0.00
Mycophenolate mofetil, MMF (NMO=5, MOG=1)	0	0.00	0	0.00	0	0.00
Rituximab (NMO=15, MOG=5)	7	46.67	1	20.00	8	40.00
Methotrexate (NMO=2, MOG=2)	1	50.00	NA	NA	1	50.00
Tocilizumab (NMO=2, MOG=0)	2	100.00	NA	NA	2	100.00

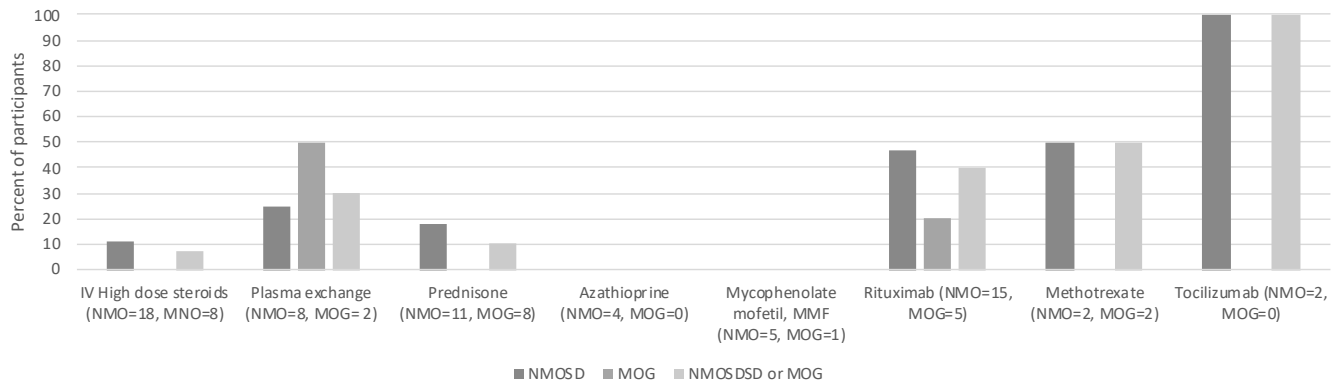


Figure 5.17: Percent of participants without side effects from treatments

Table 5.16: Median quality of life from treatments

Treatment	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Median QOL	IQR	Median QOL	IQR	Median QOL	IQR
IV High dose steroids (NMO=18, MNO=8)	2.00	2.75	3.00	1.00	2.00	2.00
Plasma exchange (NMO=8, MOG= 2)	2.50	2.25	2.00	0.00	2.00	1.75
Prednisone (NMO=11, MOG=8)	2.00	2.50	3.50	1.25	3.00	2.00
Azathioprine (NMO=4, MOG=0)	2.50	1.25	NA	NA	2.50	1.25
Mycophenolate mofetil, MMF (NMO=5, MOG=1)	1.00	4.00	3.00	0.00	2.00	3.50
Rituximab (NMO=15, MOG=5)	4.00	1.00	3.00	2.00	3.50	1.25
Methotrexate (NMO=2, MOG=2)	3.50	1.50	NA	NA	3.50	1.50
Tocilizumab (NMO=2, MOG=0)	4.50	0.50	NA	NA	4.50	0.50

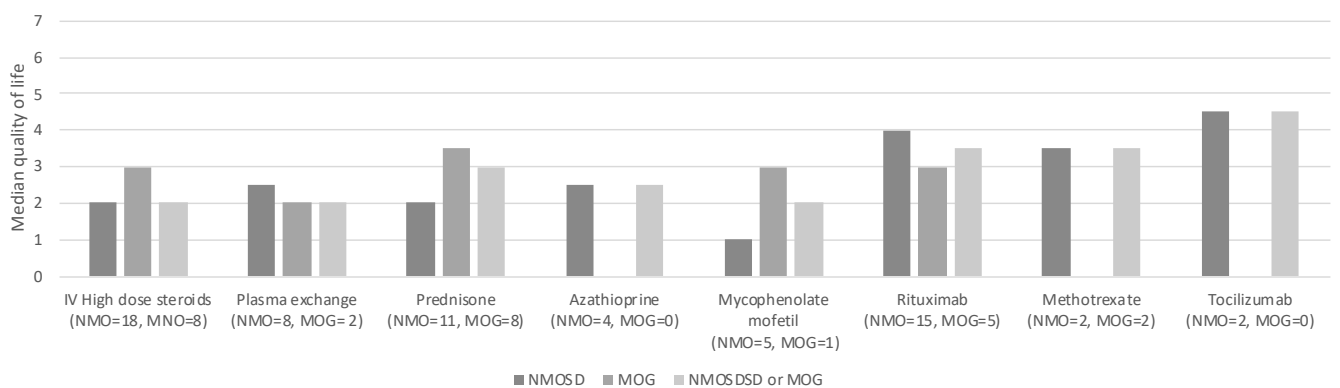


Figure 5.18: Median quality of life from treatments

Table 5.17: Median effectiveness of treatments

Treatment	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Median	IQR	Median	IQR	Median	IQR
IV High dose steroids (NMO=18, MNO=8)	4.00	1.00	4.50	1.00	4.00	1.00
Plasma exchange (NMO=8, MOG= 2)	4.50	1.00	2.50	0.50	4.00	1.75
Prednisone (NMO=11, MOG=8)	4.00	1.00	3.50	2.25	4.00	2.00
Azathioprine (NMO=4, MOG=0)	1.00	0.25	NA	NA	1.00	0.25
Mycophenolate mofetil, MMF (NMO=5, MOG=1)	4.00	3.00	5.00	0.00	4.00	3.00
Rituximab (NMO=15, MOG=5)	4.00	1.00	2.00	2.00	4.00	2.50
Methotrexate (NMO=2, MOG=2)	5.00	0.00	NA	NA	5.00	0.00
Tocilizumab (NMO=2, MOG=0)	5.00	0.00	NA	NA	5.00	0.00

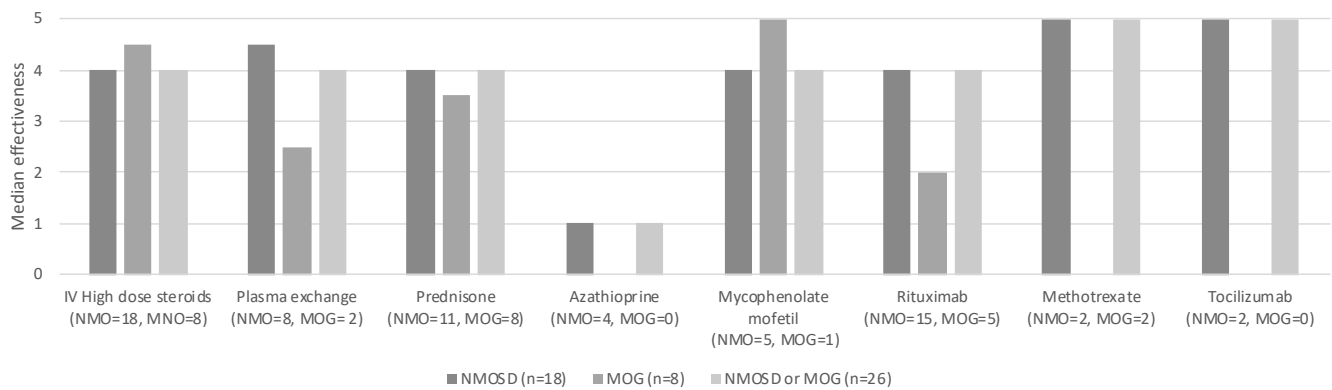


Figure 5.19: Median effectiveness of treatments

IV High dose steroids

All participants had IV high dose steroids to treat their condition. Details about quality of life (Figure 5.20), side effects, and effectiveness (Figure 5.21) are presented in Table 5.18).

NMOSD

All participants with NMOSD had IV high dose steroids (n=18, 100.00%). There were two participants (11.11%) that did not have any side effects from this treatment, and the median quality of life was 2.00 (IQR=2.75), in the “Life was distressing” range. On average, participants with NMOSD rated this treatment as effective (median = 4.00, IQR = 1.00).

The most common side effects reported were increased appetite (n=55.56%), fatigue, tiredness, or lack of energy (n=9, 50.00%), fluid retention or swelling (n=8, 44.44%), and mood changes (n=8, 44.44%).

MOG

All participants with MOG had IV high dose steroids (n=8, 100.00%), and all reported side effects. The median quality of life was 3.00 (IQR=1.00), in the

“Life was a little distressing” range. On average, participants with MOG rated this treatment as effective to very effective (median = 4.50, IQR = 1.00).

The most common side effects reported were difficulty sleeping (n=7, 87.5%), dizziness, or light-headedness (n=7, 87.5%), mood changes (n=6, 75.00%), fluid retention or swelling (n=6, 75.00%), and fatigue, tiredness, or lack of energy (n=6, 75.00%).

NMOSD or MOG

All participants with NMOSD had IV high dose steroids (n=26, 100.00%). There were two participants (5.56%) that did not have any side effects from this treatment, and the median quality of life was 2.00 (IQR=2.00), in the “Life was distressing” range. On average, participants with NMOSD rated this treatment as effective (median = 4.00, IQR = 1.00).

The most common side effects reported were Fatigue, tiredness, or lack of energy (n=15, 41.67%), increased appetite (n=15, 41.67%), mood changes (n=14, 38.89%), and fluid retention or swelling (n=14, 38.89%).

Table 5.18: IV high dose steroids

IV High dose steroids		Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
		Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Quality of life	1 Life was very distressing	8	44.44	1	12.50	9	34.62
	2 Life was distressing	4	22.22	2	25.00	6	23.08
	3 Life was a little distressing	1	5.56	4	50.00	5	19.23
	4 Life was average	3	16.67	0	0.00	3	11.54
	5 Life was good	2	11.11	1	12.50	3	11.54
	6 Life was very good	0	0.00	0	0.00	0	0.00
	7 Life was great	0	0.00	0	0.00	0	0.00
Side effects	No side effects	2	11.11	0	0.00	2	5.56
	Bleeding or bruising more easily than normal	2	11.11	3	37.50	5	13.89
	Fluid retention or swelling	8	44.44	6	75.00	14	38.89
	Dizziness, or light-headedness	4	22.22	7	87.50	11	30.56
	Headache	6	33.33	3	37.50	9	25.00
	Forgetfulness	2	11.11	4	50.00	6	16.67
	Fatigue, tiredness, or lack of energy	9	50.00	6	75.00	15	41.67
	Increased appetite	10	55.56	5	62.50	15	41.67
	Loss of appetite	1	5.56	1	12.50	2	5.56
	Irregular menstrual periods	1	5.56	0	0.00	1	2.78
	Constipation	6	33.33	3	37.50	9	25.00
	Diarrhoea	0	0.00	0	0.00	0	0.00
	Heartburn or indigestion	4	22.22	3	37.50	7	19.44
	Nausea and vomiting	2	11.11	4	50.00	6	16.67
	Mood changes	8	44.44	6	75.00	14	38.89
	Joint pain	3	16.67	3	37.50	6	16.67
	Muscle cramps or spasms	3	16.67	0	0.00	3	8.33
	Persistent hiccups	0	0.00	0	0.00	0	0.00
	Excessive sweating	5	27.78	5	62.50	10	27.78
	Flushing	2	11.11	0	0.00	2	5.56
	Infusion site pain/reactions	2	11.11	0	0.00	2	5.56
	Itchy, painful, dry, or red skin	3	16.67	2	25.00	5	13.89
	Skin rash	1	5.56	3	37.50	4	11.11
	Difficulty sleeping	5	27.78	7	87.50	12	33.33
	Other	3	16.67	0	0.00	3	8.33
Effectiveness	Ineffective	3	16.67	0	0.00	3	11.54
	Somewhat effective	0	0.00	1	12.50	1	3.85
	Moderately effective	1	5.56	0	0.00	1	3.85
	Effective	7	38.89	3	37.50	10	38.46
	Very effective	7	38.89	4	50.00	11	42.31

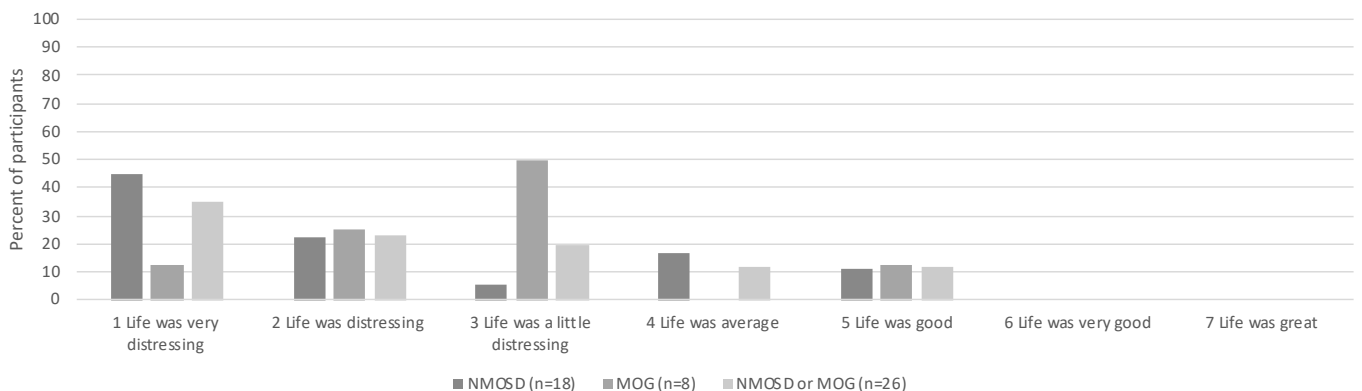


Figure 5.20: Quality of life from IV high dose steroids

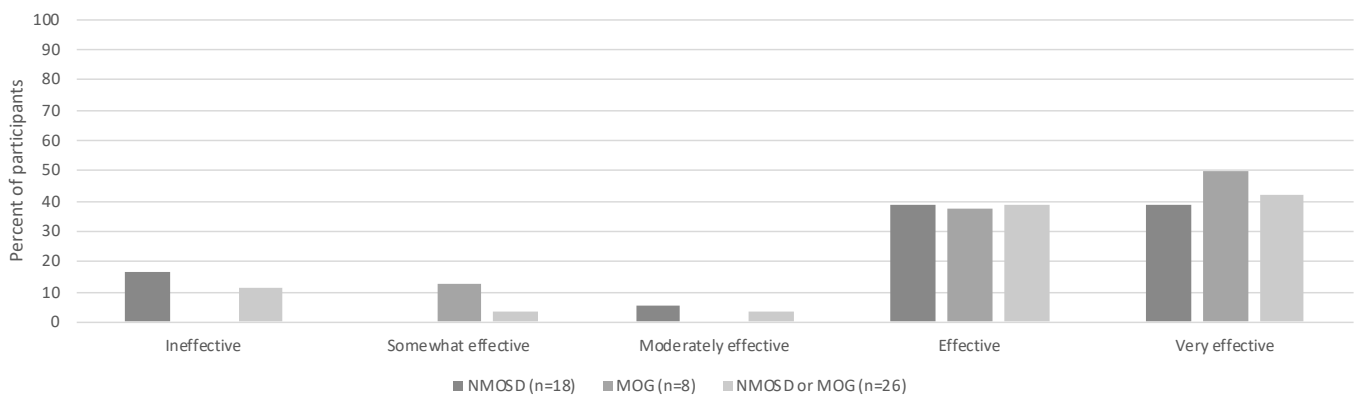


Figure 5.21: Effectiveness of IV high dose steroids

Plasma exchange (PLEX)

A total of 10 participants had plasma exchange to treat their condition. Details about quality of life (Figure 5.22), side effects, and effectiveness (Figure 5.23) are presented in Table 5.19)

NMOSD

There were eight participants with NMOSD (44.44%) that had plasma exchange. The median quality of life was 2.50 (IQR = 2.25), in the “life was a little distressing” to “life was distressing” range. On average, participants with NMOSD rated this treatment as to effective to very effective (median = 4.50, IQR = 1.00).

Two participants (25.00%) reported no side effects from this treatment. The most common side effects

reported were dizziness or light-headedness (n=3, 37.50%), and chills (n=2, 25.00%).

NMOSD and MOG

There were 10 participants with NMOSD or MOG (38.46%) that had plasma exchange, three of these participants (30.00%) reported no side effects from this treatment. The median quality of life was 2.00 (IQR = 1.75), in the “life was distressing” range. On average, participants with NMOSD or MOG rated this treatment as to effective (median = 4.00, IQR = 1.75).

Three participants (30.00%) reported no side effects from this treatment. The most common side effects reported were dizziness or light-headedness (n=4, 40.00%), and chills (n=2, 20.00%).

Table 5.19: Plasma exchange

Plasma exchange (PLEX)		Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
		Number (n=8)	Percent	Number (n=2)	Percent	Number (n=10)	Percent
Quality of life	1 Life was very distressing	3	37.50	0	0.00	3	30.00
	2 Life was distressing	1	12.50	2	100.00	3	30.00
	3 Life was a little distressing	2	25.00	0	0.00	2	20.00
	4 Life was average	1	12.50	0	0.00	1	10.00
	5 Life was good	1	12.50	0	0.00	1	10.00
	6 Life was very good	0	0.00	0	0.00	0	0.00
	7 Life was great	0	0.00	0	0.00	0	0.00
Side effects	No side effects	2	25.00	1	50.00	3	30.00
	Skin rash	0	0.00	0	0.00	0	0.00
	Muscle cramps or spasms	1	12.50	0	0.00	1	10.00
	Nausea and vomiting	0	0.00	1	50.00	1	10.00
	Fever	0	0.00	0	0.00	0	0.00
	Chills	2	25.00	0	0.00	2	20.00
	Numbness or pins and needles in your hands or feet	0	0.00	1	50.00	1	10.00
	Dizziness or light-headedness	3	37.50	1	50.00	4	40.00
	Other	4	50.00	0	0.00	4	40.00
Effectiveness	Ineffective	1	12.50	0	0.00	1	10.00
	Somewhat effective	0	0.00	1	50.00	1	10.00
	Moderately effective	0	0.00	1	50.00	1	10.00
	Effective	3	37.50	0	0.00	3	30.00
	Very effective	4	50.00	0	0.00	4	40.00

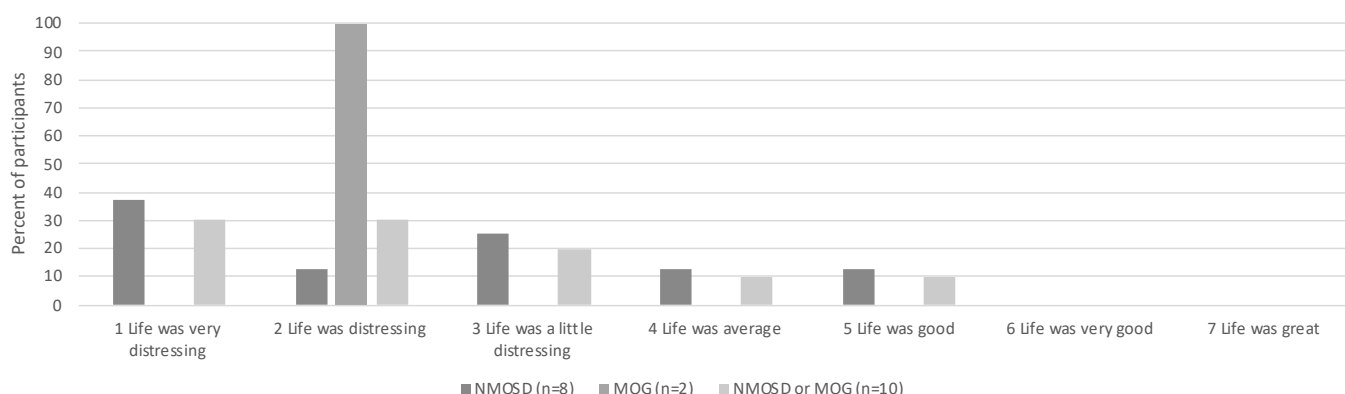


Figure 5.22: Quality of life from plasma exchange

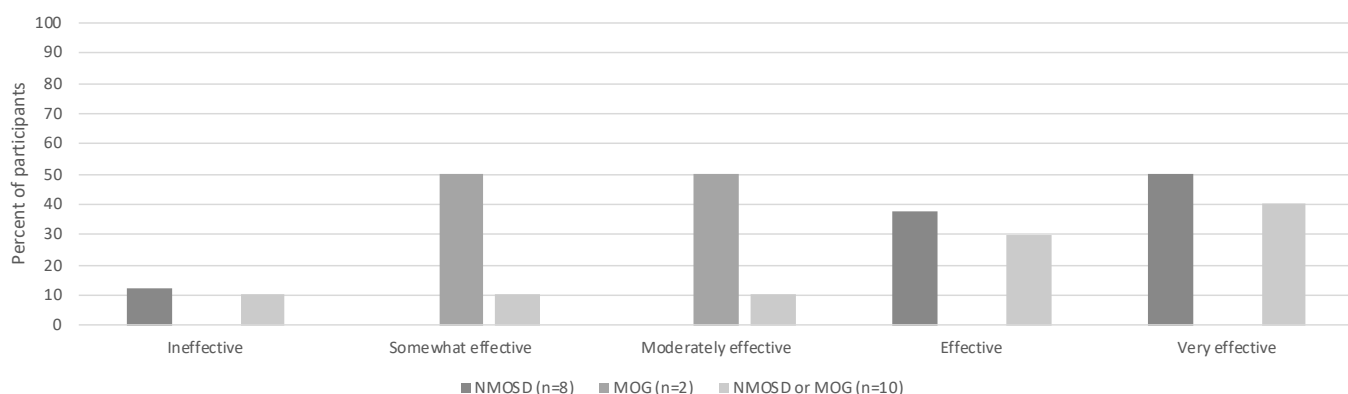


Figure 5.23: Effectiveness of plasma exchange

Prednisone

A total of 19 participants had prednisone to treat their condition. Details about quality of life (Figure 5.24), side effects, and effectiveness (Figure 5.25) are presented in Table 5.20)

NMOSD

There were 11 participants with NMOSD (64.11%) that had prednisone. The median quality of life was 2.00 (IQR = 2.50), in the “life was distressing” range. On average, participants with NMOSD rated this treatment as to effective (median = 4.00, IQR = 1.00)

Two participants (18.18%) reported no side effects from this treatment. The most commonly reported side effects were increased appetite (n=7, 63.64%), weight gain (n=54, 5.45%), and difficulty sleeping (n=4, 36.36%).

MOG

All participants with MOG had that had prednisone (n=8, 100.00%), all had side effects from this treatment. The median quality of life was 3.5 (IQR = 1.25), in the “life was a little distressing” to “life was

average” range. On average, participants with MOG rated this treatment as moderately effective to effective (median = 3.50, IQR = 2.25).

All participants with MOG had side effects from this treatment, the most common side effects were weight gain (n=7, 87.50%), difficulty (n=7, 87.50%), increased appetite (n=6, 75.00%), fluid retention or swelling (n=6, 75.00%), mood changes, or mood swings (n=6, 75.00%).

NMOSD or MOG

There were 19 participants with NMOSD or MOG (73.08%) that had prednisone. The median quality of life was 3.00 (IQR = 2.00), in the “life was a little distressing” range. On average, participants with NMOSD or MOG rated this treatment as to effective (median = 4.00, IQR = 2.00)

Two participants (10.53%) reported no side effects from this treatment. The most common side effects were increased appetite (n=13, 68.42%), weight gain (n=12, 63.16%), difficulty sleeping (n=11, 57.89%), fluid retention or swelling (n=9, 47.37%), and mood changes, or mood swings (n=9, 47.37%)

Table 5.20: Prednisone

Prednisone		Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
		Number (n=11)	Percent	Number (n=8)	Percent	Number (n=19)	Percent
Status	Still taking this medication	4	36.36	5	62.50	9	47.37
	No longer needs this medication	6	54.55	2	25.00	8	42.11
	Stopped due to side effects	1	9.09	1	12.50	2	10.53
	Stopped due to not working	0	0.00	0	0.00	0	0.00
Quality of life	1 Life was very distressing	3	27.27	1	12.50	4	21.05
	2 Life was distressing	4	36.36	1	12.50	5	26.32
	3 Life was a little distressing	0	0.00	2	25.00	2	10.53
	4 Life was average	4	36.36	4	50.00	8	42.11
	5 Life was good	0	0.00	0	0.00	0	0.00
	6 Life was very good	0	0.00	0	0.00	0	0.00
	7 Life was great	0	0.00	0	0.00	0	0.00
Side effects	No side effects	2	18.18	0	0.00	2	10.53
	Bleeding or bruising more easily than normal	1	9.09	2	25.00	3	15.79
	Fluid retention or swelling	3	27.27	6	75.00	9	47.37
	Poor wound healing	1	9.09	3	37.50	4	21.05
	High blood pressure	2	18.18	1	12.50	3	15.79
	Irregular heart beat	0	0.00	2	25.00	2	10.53
	Dizziness or light-headedness	2	18.18	3	37.50	5	26.32
	Headache	2	18.18	5	62.50	7	36.84
	Blurred or double vision	2	18.18	4	50.00	6	31.58
	Bulging eyes	0	0.00	0	0.00	0	0.00
	Cataracts	0	0.00	1	12.50	1	5.26
	Increased appetite	7	63.64	6	75.00	13	68.42
	Loss of appetite	0	0.00	1	12.50	1	5.26
	Weight gain	5	45.45	7	87.50	12	63.16
	Irregular menstrual periods	0	0.00	0	0.00	0	0.00
	Constipation	0	0.00	4	50.00	4	21.05
	Diarrhoea	3	27.27	0	0.00	3	15.79
	Nausea and vomiting	0	0.00	3	37.50	3	15.79
	Stomach bloating	2	18.18	5	62.50	7	36.84
	Increased infections	1	9.09	2	25.00	3	15.79
	Anxiety or nervousness	2	18.18	2	25.00	4	21.05
	Mood changes, or mood swings	3	27.27	6	75.00	9	47.37
	Muscle cramps or spasms	1	9.09	0	0.00	1	5.26
	Acne	1	9.09	3	37.50	4	21.05
	Excessive growth of body and facial hair	3	27.27	2	25.00	5	26.32
	Excessive sweating	2	18.18	5	62.50	7	36.84
	Flushing	2	18.18	1	12.50	3	15.79
	Difficulty sleeping	4	36.36	7	87.50	11	57.89
	Other	1	9.09	0	0.00	1	5.26
Effectiveness	Ineffective	1	9.09	0	0.00	1	5.26
	Somewhat effective	1	9.09	2	25.00	3	15.79
	Moderately effective	1	9.09	2	25.00	3	15.79
	Effective	5	45.45	1	12.50	6	31.58
	Very effective	3	27.27	3	37.50	6	31.58

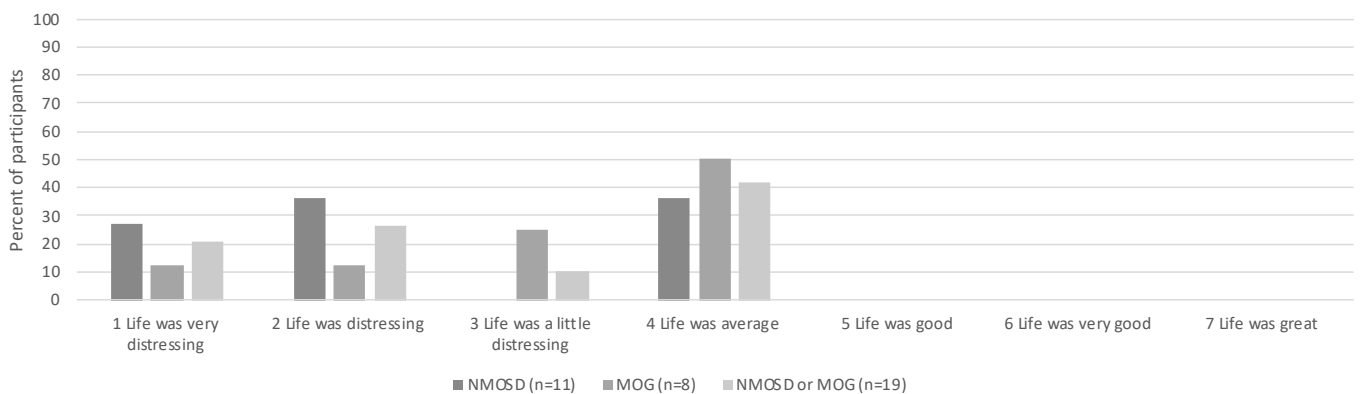


Figure 5.24: Quality of life from prednisone

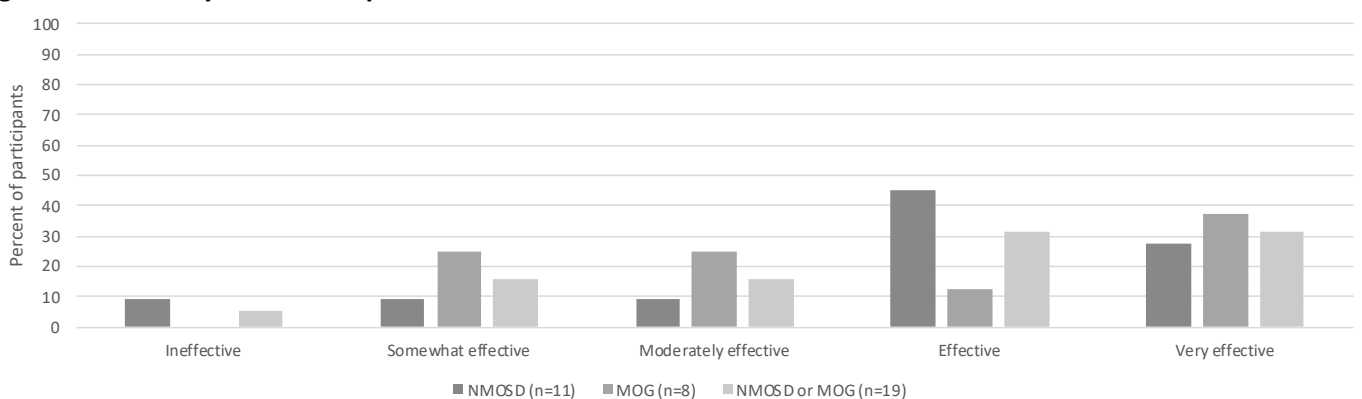


Figure 5.25: Effectiveness of prednisone

Rituximab

A total of 20 participants had rituximab to treat their condition. Details about quality of life (Figure 5.26), side effects, and effectiveness (Figure 5.27) are presented in Table 5.21).

NMOSD

There were 15 participants with NMOSD (83.33%) that had rituximab. The median quality of life was 4.00 (IQR = 1.00), in the “life was average” range. On average, participants with NMOSD rated this treatment as effective (median = 4.00, IQR = 1.00).

Seven participants (46.67%) reported no side effects from this treatment. The most common side effects reported were Numbness or pins and needles in

your hands or feet, A general feeling of being unwell (n=3, 20.00%).

NMOSD or MOG

There were 20 participants with NMOSD or MOG (76.92%) that had rituximab. The median quality of life was 3.50 (IQR = 1.25), in the “life was a little distressing” to “life was average” range. On average, participants with NMOSD rated this treatment as effective (median = 4.00, IQR = 2.00).

Eight (40.00%) reported no side effects from this treatment. The most commonly reported side effects were a general feeling of being unwell (n=6, 30.00%) , hair loss or thinning (n=5, 25.00%), and difficulty sleeping (n=5, 25.00%).

Table 5.21: Rituximab

Rituximab		Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
		Number (n=15)	Percent	Number (n=5)	Percent	Number (n=20)	Percent
Status	Still taking this medication	11	73.33	4	80.00	15	75.00
	No longer needs this medication	1	6.67	0	0.00	1	5.00
	Stopped due to side effects	2	13.33	1	20.00	3	15.00
	Stopped due to not working	1	6.67	0	0.00	1	5.00
Quality of life	1 Life was very distressing	3	20.00	1	20.00	4	20.00
	2 Life was distressing	0	0.00	0	0.00	0	0.00
	3 Life was a little distressing	4	26.67	2	40.00	6	30.00
	4 Life was average	5	33.33	0	0.00	5	25.00
	5 Life was good	1	6.67	2	40.00	3	15.00
	6 Life was very good	2	13.33	0	0.00	2	10.00
	7 Life was great	0	0.00	0	0.00	0	0.00
Side effects	No side effects	7	46.67	1	20.00	8	40.00
	Fatigue	1	6.67	0	0.00	1	5.00
	Bleeding or bruising more easily than normal	1	6.67	1	20.00	2	10.00
	High blood pressure	0	0.00	0	0.00	0	0.00
	Change in sense of smell or taste	1	6.67	1	20.00	2	10.00
	Numbness or pins and needles in your hands or feet	3	20.00	1	20.00	4	20.00
	Blocked or stuffy nose	2	13.33	0	0.00	2	10.00
	Cough	0	0.00	0	0.00	0	0.00
	Ear pain and/or buzzing, or other persistent noise in the ears	1	6.67	1	20.00	2	10.00
	Conjunctivitis	0	0.00	0	0.00	0	0.00
	A general feeling of being unwell	3	20.00	3	60.00	6	30.00
	Loss of appetite	0	0.00	1	20.00	1	5.00
	Weight loss	0	0.00	1	20.00	1	5.00
	Constipation	0	0.00	0	0.00	0	0.00
	Diarrhoea	0	0.00	1	20.00	1	5.00
	Heartburn or indigestion	1	6.67	2	40.00	3	15.00
	Sore mouth, or mouth ulcers	1	6.67	1	20.00	2	10.00
	Shingles (herpes zoster infection)	1	6.67	0	0.00	1	5.00
	Anxiety or nervousness	0	0.00	1	20.00	1	5.00
	Muscle pain, or weakness	2	13.33	1	20.00	3	15.00
	Excessive sweating or night sweating	2	13.33	2	40.00	4	20.00
	Hair loss or thinning	2	13.33	3	60.00	5	25.00
	Difficulty sleeping	2	13.33	3	60.00	5	25.00
	Other	3	20.00	0	0.00	3	15.00
	Ineffective	2	13.33	0	0.00	2	10.00
Effectiveness (n=19)	Somewhat effective	0	0.00	3	60.00	3	15.00
	Moderately effective	1	6.67	0	0.00	1	5.00
	Effective	5	33.33	1	20.00	6	30.00
	Very effective	6	40.00	1	20.00	7	35.00

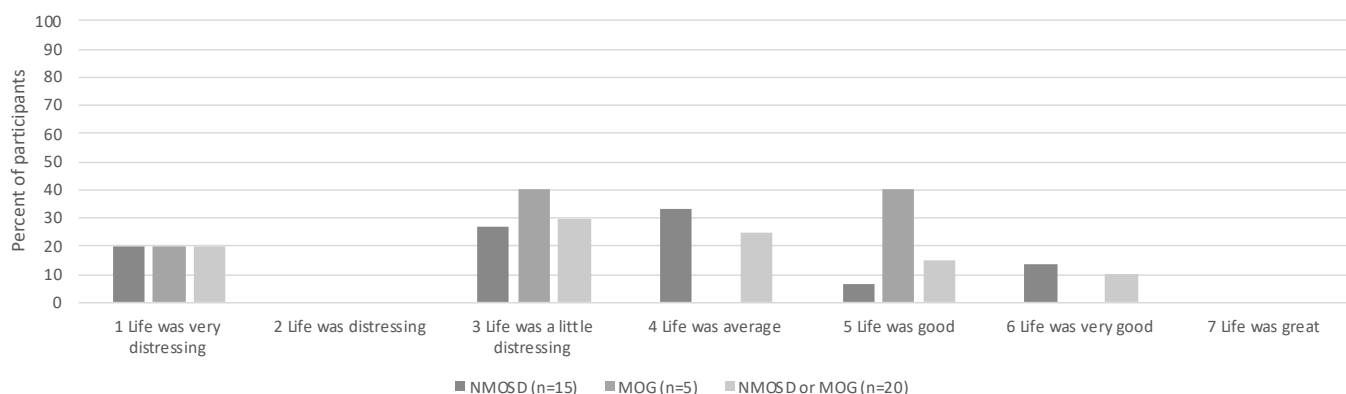


Figure 5.26: Quality of life from rituximab

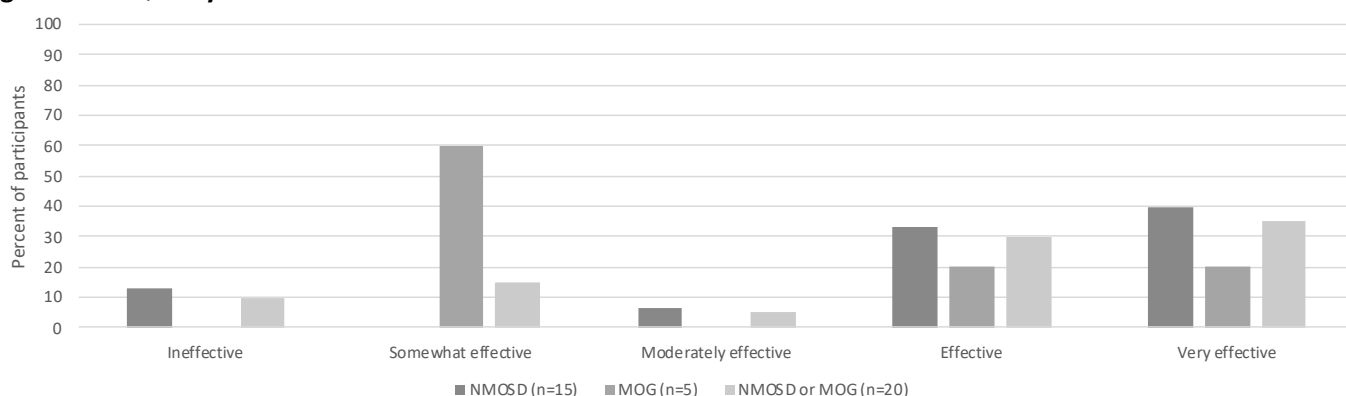


Figure 5.27a: Effectiveness of rituximab

Allied health

Participants were asked about allied health services they used (Table 5.22, Figure 5.28), the quality of life from these therapies (Table 5.23, Figure 5.29), and how effective they found them (Table 5.29, Figure 5.30).

NMOSD

The most common allied health service used by participants with NMOSD was occupational therapy (n=10, 55.56%), followed by physiotherapy (n=9, 50.00%) and psychology (n=8, 44.44%).

The median quality of life from the most common allied health services was in the “life was a little distressing” range, occupational therapy (median=3.00, IQR=2.00), physiotherapy (median=3.00, IQR=2.00) and psychology (median=3.00, IQR=1.50).

The average effectiveness from the most commonly used allied health services was in the moderately effective to effective range, occupational therapy (median = 3, IQR = 0.25), physiotherapy (median=4, IQR=2) and psychology (median = 3, IQR=1).

MOG

The most common allied health services used by participants with MOG were physiotherapy (n=4, 50.00%), psychology (n=2, 25.00%), and podiatry (n=2, 25.00%).

NMOSD and MOG

The most common allied health service used by participants with NMOSD or MOG was occupational therapy (n=13, 50.00%), followed by physiotherapy (n=11, 42.31%) and psychology (n=10, 38.46%).

The median quality of life from the most common allied health services was in the “life was a little distressing” range, occupational therapy (median=3.00, IQR=2.00), physiotherapy (median=3.00, IQR=2.00) and psychology (median=3.00, IQR=1.00).

The median effectiveness from the most common allied health services was in the moderately effective range, occupational therapy (median=3.00, IQR=0.25), physiotherapy (median=3.00, IQR=1.00) and psychology (median=3.00, IQR=1.00).

Table 5.22: Allied health

Allied health	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Speech therapist	2	11.11	0	0.00	2	7.69
Physiotherapist	9	50.00	4	50.00	13	50.00
Occupational therapist	10	55.56	1	12.50	11	42.31
Psychologist	8	44.44	2	25.00	10	38.46
Neuropsychologist	1	5.56	0	0.00	1	3.85
Dietician	2	11.11	1	12.50	3	11.54
Social worker	2	11.11	0	0.00	4	15.38
Podiatrist	3	16.67	2	25.00	5	19.23

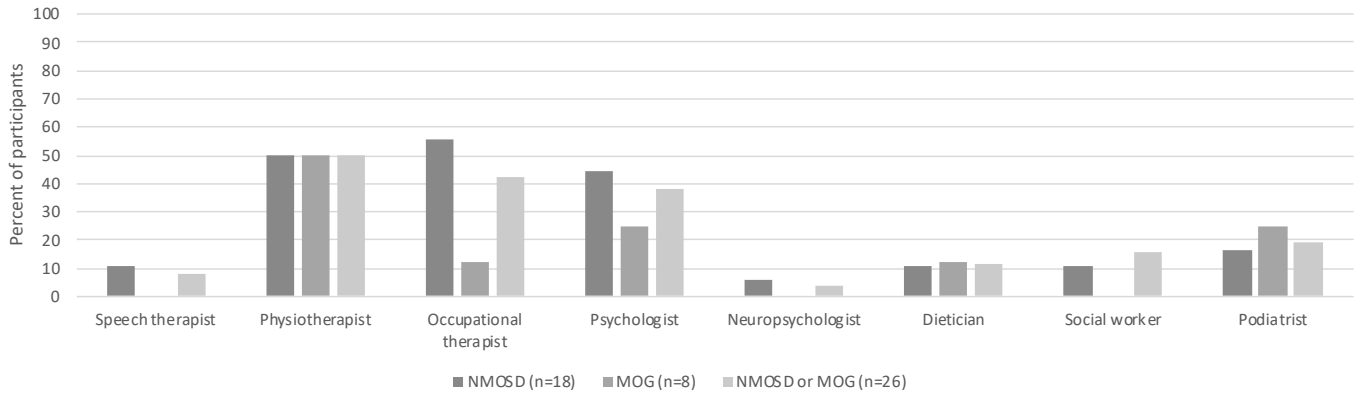


Figure 5.28: Allied health

Table 5.23: Median quality of life from allied health

Allied health	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Median	IQR	Number (n=8)	Percent	Number (n=26)	Percent
Speech therapist	2	0.00	NA	NA	2	0.00
Physiotherapist	3	2.00	4	2.00	3	2.00
Occupational therapist	3	2.00	NA	NA	3	2.00
Psychologist	3	1.50	2.5	0.50	3	1.00
Neuropsychologist	2	0.00	NA	NA	2	0.00
Dietician	1.5	0.50	4	0.00	2	1.50
Social worker	1	0.00	NA	NA	1	0.00
Podiatrist	4	1.00	6	0.00	4	2.00

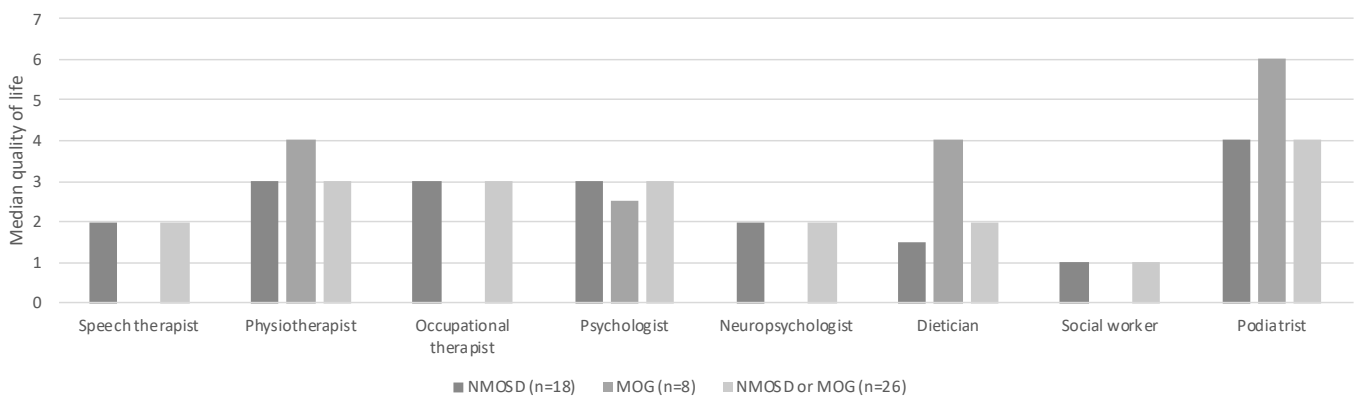


Figure 5.29: Median quality of life from allied health

5.24: Median effectiveness of allied health

Allied health	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Speech therapist	4	0.00	NA	NA	4	0.00
Physiotherapist	4	2.00	3	0.00	3	1.00
Occupational therapist	3	0.25	NA	NA	3	0.25
Psychologist	3	1.00	2.5	0.50	3	1.00
Neuropsychologist	1	0.00	NA	NA	1	0.00
Dietician	2.5	1.50	2	0.00	2	1.50
Social worker	3.5	1.50	NA	NA	3.5	1.50
Podiatrist	3	0.50	4	0.00	3	1.00

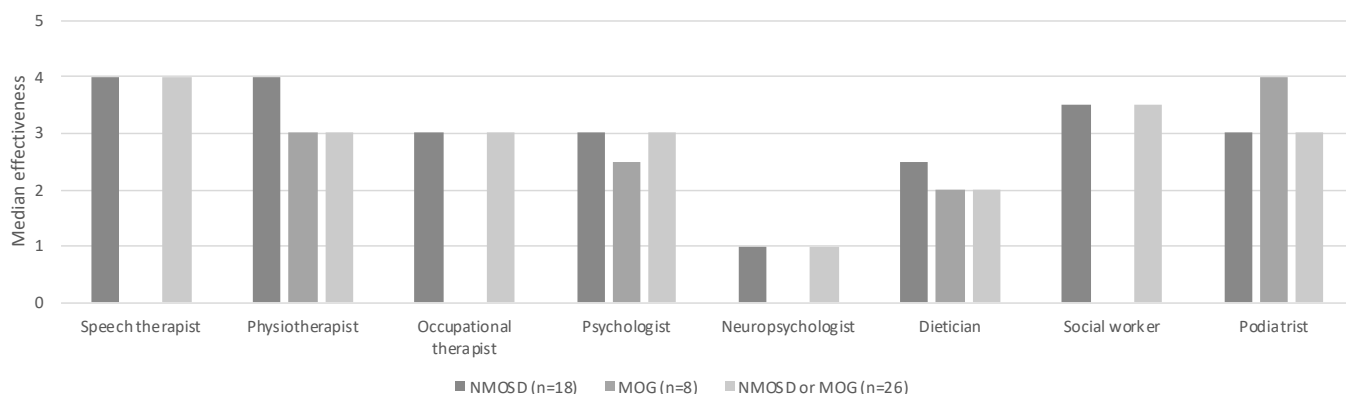


Figure 5.30: Median effectiveness of allied health

Lifestyle changes

Participants were asked about any lifestyle changes they had made since being diagnosed with their condition (Table 5.25, Figure 5.31), the quality of life from these changes (Table 5.26, Figure 5.32), and how effective they found them (Table 5.27, Figure 5.33).

NMOSD

Almost all participants (n=15, 83.33%) with NMOSD had made lifestyle changes to help manage their condition. The most common lifestyle change was exercise (n=13, 72.22%), followed by diet changes (n=7, 38.89%).

The median quality of life from the most common lifestyle changes was in the “life was average” range, exercise (median=4.00, IQR=2.00), and diet (median=4.00, IQR=2.00).

The median effectiveness of exercise was in the somewhat effective range (median=2.00, IQR=2.00), and diet was in the effective range (median=4.00, IQR=1.00).

MOG

All participants with MOG had made lifestyle changes to help manage their condition. The most common lifestyle change was exercise (n=7, 87.50%), followed by diet changes (n=5, 62.50%).

The median quality of life from exercise was in the “life was average” range (median=4.00, IQR=1.50), and diet in the “life was a good” range (median=5.00, IQR=2.00).

The median effectiveness of exercise was in the somewhat effective range (median=2.00, IQR=1.50), and diet was in the moderately effective range (median=3.00, IQR=2.00).

NMOSD or MOG

Overall, for NMOSD or MOG participants the most common lifestyle changes were exercise (n=20, 76.92%) and diet (n=12, 46.15%).

The median quality of life from the most common lifestyle changes was in the “life was average” range, exercise (median=4.00, IQR=2.00), and diet (median=4.00, IQR=2.25).

The median effectiveness of exercise was in the effective range (median=4.00, IQR=2.00), and diet was in the somewhat effective to moderately effective range (median=2.50, IQR=2.00).

Table 5.25: Lifestyle changes

Lifestyle changes	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Diet changes	7	38.89	5	62.50	12	46.15
Quit smoking (NMOSD=7, MOG = 3)	1	14.29	0	0.00	1	10.00
Exercise	13	72.22	7	87.50	20	76.92
Reduce alcohol (NMOSD=9, MOG = 5)	6	66.67	2	40.00	8	57.14

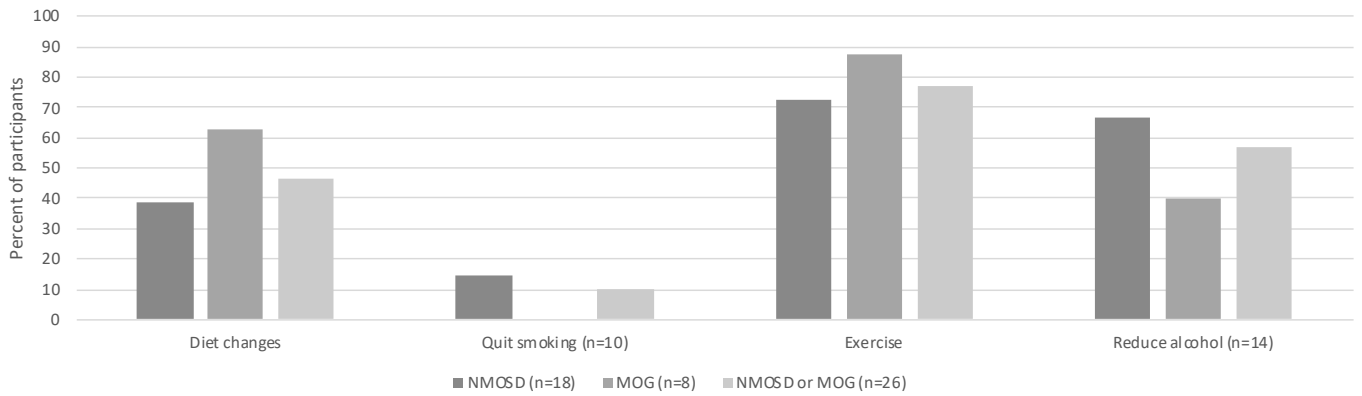


Figure 5.31: Lifestyle changes

Table 5.26: Median quality of life from lifestyle changes

Lifestyle changes	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	median	iqr	median	iqr	median	iqr
Diet changes	4.00	2.00	5.00	1.00	4.00	2.25
Quit smoking (NMO=7, MOG = 3)	2.00	0.00	NA	NA	2.00	0.00
Exercise	4.00	2.00	4.00	1.50	4.00	2.00
Reduce alcohol (NMO=9, MOG = 5)	4.50	1.00	3.50	0.50	4.00	1.00

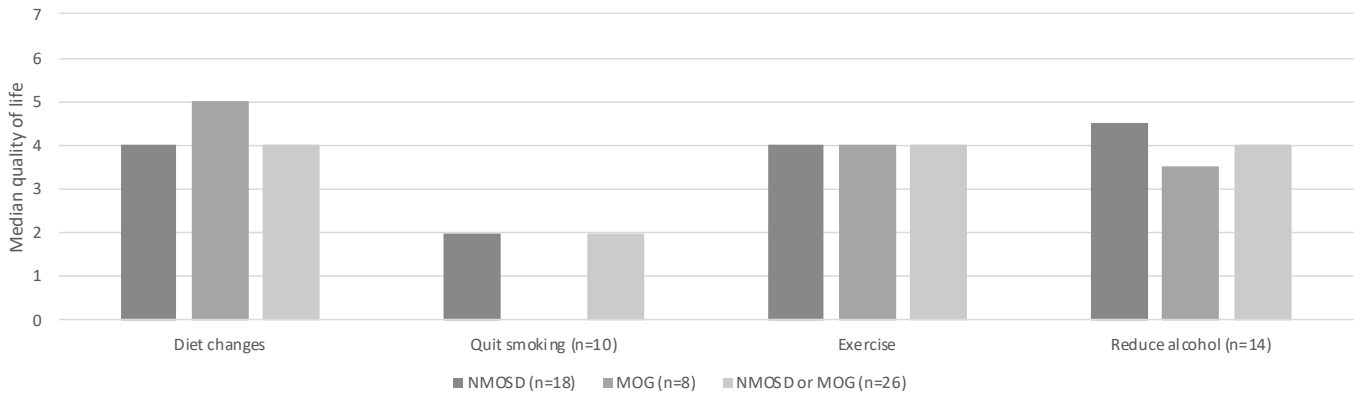


Figure 5.32: Median effectiveness of lifestyle changes

Lifestyle changes	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	median	iqr	median	iqr	median	iqr
Diet changes	2.00	2.00	3.00	2.00	2.50	2.00
Quit smoking (NMO=7, MOG = 3)	5.00	0.00	NA	NA	5.00	0.00
Exercise	4.00	1.00	2.00	1.50	4.00	2.00
Reduce alcohol (NMO=9, MOG = 5)	2.00	2.25	4.00	0.00	3.00	2.25

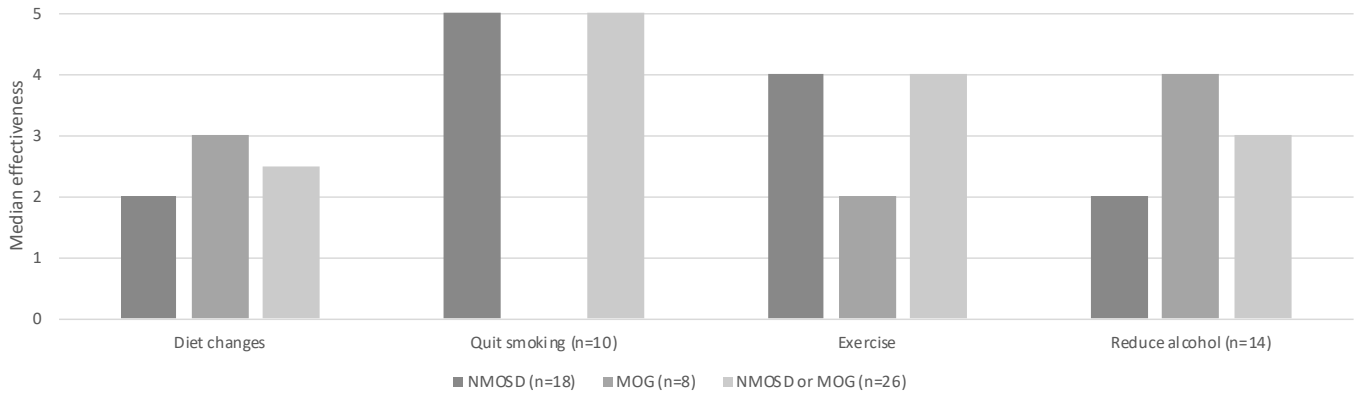


Figure 5.33: Median effectiveness of lifestyle changes

Complementary therapies

Participants were asked about complementary therapies they used (Table 5.28, Figure 5.34), the quality of life from these therapies (Table 5.29, Figure 5.35), and how effective they found them (Table 5.30, Figure 5.36).

NMOSD

Over 75% of participants with NMOSD used at least one type of complementary therapy (n=14, 77.78%). The most common complementary therapy used was mindfulness or relaxation techniques (n=10, 55.56%), followed by supplements (n=9, 50.00%), and massage therapy (n=6, 33.33%).

The average quality of life from the most common complementary therapies used was in the “life was average” range; mindfulness or relaxation techniques (median=4.0, IQR=2.50), supplements (median=4.0, IQR=2.00) and massage therapy (median=4.0, IQR=1.50).

The average effectiveness from mindfulness or relaxation techniques was in the moderately effective to effective range (median=3.5, IQR=1.00), for supplements in the somewhat effective range (median=2.0, IQR=1.00) and for massage therapy in the moderately effective to effective range (median=3.5, IQR=1.75).

MOG

There were 75% of participants with MOG that used at least one type of complementary therapy. The most common complementary therapy used was mindfulness or relaxation techniques (n=6, 75.00%), followed by supplements (n=3, 37.50%).

The average quality of life from the most common complementary therapies used was in the “life was average” range; mindfulness or relaxation techniques (median=4.0, IQR=1.50), supplements (median=4.0, IQR=0.5).

The average effectiveness from mindfulness or relaxation techniques was in the moderately effective range (median=3.0, IQR=0.75), and in the moderately effective range for supplements (median=2.0, IQR=1.00).

NMOSD or MOG

Over 75% of participants with NMOSD or MOG used at least one type of complementary therapy (n=20, 76.92%). The most common complementary therapy used was mindfulness or relaxation techniques (n=16, 61.54%), followed by supplements (n=12, 46.15%), and massage therapy (n=7, 26.92%).

The average quality of life from the most common complementary therapies used was in the “life was average” range; mindfulness or relaxation techniques (median=4.0, IQR=2.00), supplements (median=4.0, IQR=1.25) and massage therapy (median=4.0, IQR=1.50).

The average effectiveness from mindfulness or relaxation techniques was in the moderately effective range (median=3.0, IQR=1.00), for supplements in the somewhat effective to moderately effective range (median=2.50, IQR=1.00) and for massage therapy in the moderately effective range (median=3.00, IQR=1.50).

Table 5.28: Complementary therapies

Complementary therapies	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Massage therapy	4	1.50	3	0.00	4	1.50
Acupuncture	4	0.00	NA	NA	4	0.00
Supplements	4	2.00	4	0.50	4	1.25
Mindfulness or relaxation	4	2.50	4	1.50	4	2.00
Naturopathy	3	1.00	NA	NA	3	1.00

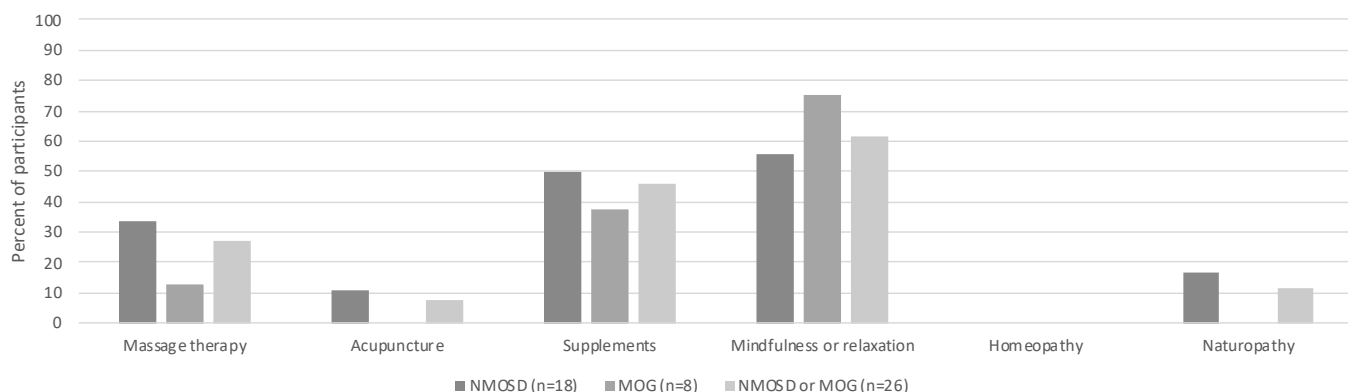


Figure 5.34: Complementary therapies

Table 5.29: Median quality of life from complementary therapies

Complementary therapies	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Median	IQR	Median	IQR	Median	IQR
Massage therapy	4.00	1.50	3.00	0.00	4.00	1.50
Acupuncture	4.00	0.00	NA	NA	4.00	0.00
Supplements	4.00	2.00	4.00	0.50	4.00	1.25
Mindfulness or relaxation	4.00	2.50	4.00	1.50	4.00	2.00
Naturopathy	3.00	1.00	NA	NA	3.00	1.00

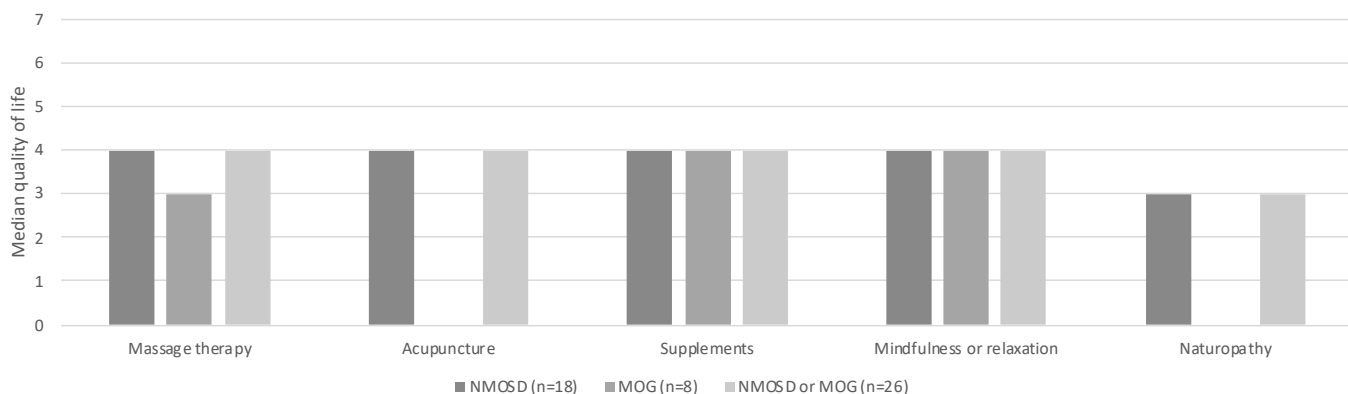


Figure 5.35: Median quality of life from complementary therapies

Table 5.30: Median effectiveness from complementary therapies

Complementary therapies	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Median	IQR	Median	IQR	Median	IQR
Massage therapy	3.50	1.75	3.00	0.00	3.00	1.50
Acupuncture	3.00	1.00	NA	NA	3.00	1.00
Supplements	2.00	1.00	3.00	1.00	2.50	1.00
Mindfulness or relaxation	3.50	1.00	3.00	0.75	3.00	1.00
Naturopathy	2.00	1.00	NA	NA	2.00	1.00

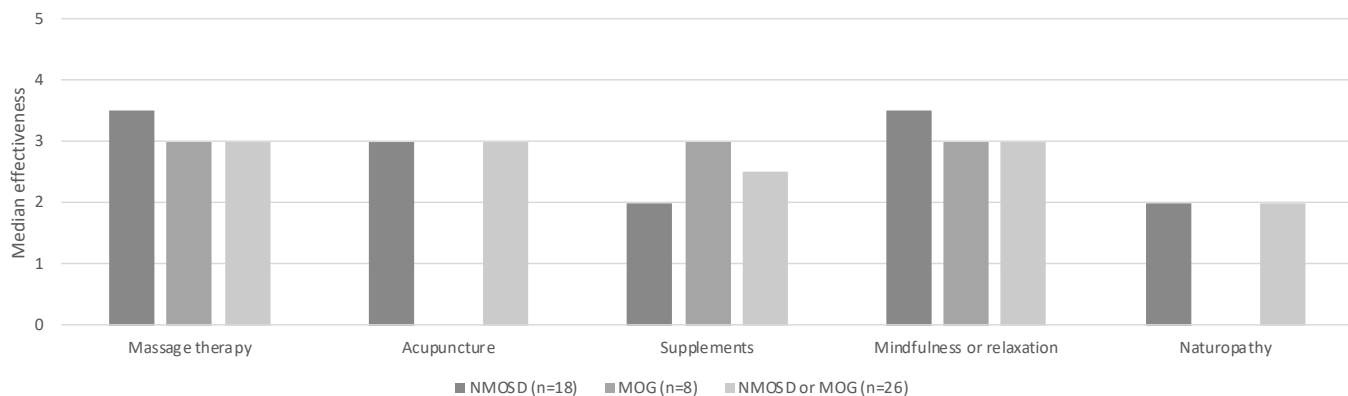


Figure 5.36: Median effectiveness from complementary therapies

Clinical trials discussions

In the online questionnaire, participants were asked if they had discussions with their doctor about clinical trials, and if they did, who initiated the discussion (Table 5.31, Figure 5.37).

NMOSD

The majority of participants with NMOSD did not have any conversations about clinical trials with their doctor (n=15, 83.33%). The doctors of two participants (11.11%) brought up the topic, and one (5.56%) participant brought the topic with their doctor.

MOG

The majority of participants with MOG did not have any conversations about clinical trials with their doctor (n=7, 87.50%), and one participant (12.50%) brought the topic with their doctor.

NMOSD or MOG

The majority of participants with NMOSD or MOG did not have any conversations about clinical trials with their doctor (n=22, 84.62%). The doctors of two participants (7.69%) brought up the topic, and two participants (7.69%) brought the topic with their doctor.

Table 5.31: Discussions about clinical trials

Clinical trial discussions	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
I brought up the topic of clinical trials with my doctor for discussion	1	5.56	1	12.50	2	7.69
My doctor brought up the topic of clinical trials for discussion	2	11.11	0	0.00	2	7.69
No one has ever spoken to me about clinical trials	15	83.33	7	87.50	22	84.62

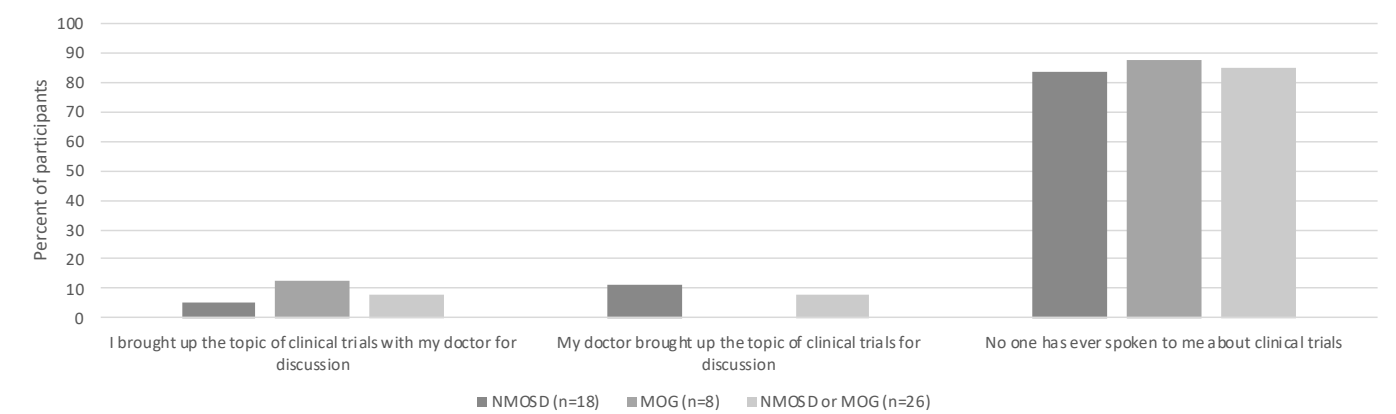


Figure 5.37: Discussions about clinical trials

Clinical trial participation

As a follow up question, participants were asked if they had taken part in a clinical trial, and if they had not taken part if they were interested in taking part. No participants in this study had taken part in a clinical trial (Table 5.32, Figure 5.38).

NMOSD

The majority of participants with NMOSD were interested in taking part in a clinical trial (n=16, 88.89%), and two participants (11.11%) that were not interested in taking part in a clinical trial.

MOG

The majority of participants with MOG were interested in taking part in a clinical trial (n=7, 87.50%), and one participant (12.50%) that were not interested in taking part in a clinical trial.

NMOSD or MOG

Overall, The majority of participants with NMOSD or MOG were interested in taking part in a clinical trial (n=23, 88.46%), and three participant (11.54%) that were not interested in taking part in a clinical trial.

Table 5.32: Clinical trial participation

Clinical trial participation	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Has not participated in a clinical trial and does not want to	2	11.11	1	12.50	3	11.54
Has not participated in a clinical trial but would like to if there is one	16	88.89	7	87.50	23	88.46
Has participated in a clinical trial	0	0.00	0	0.00	0	0.00

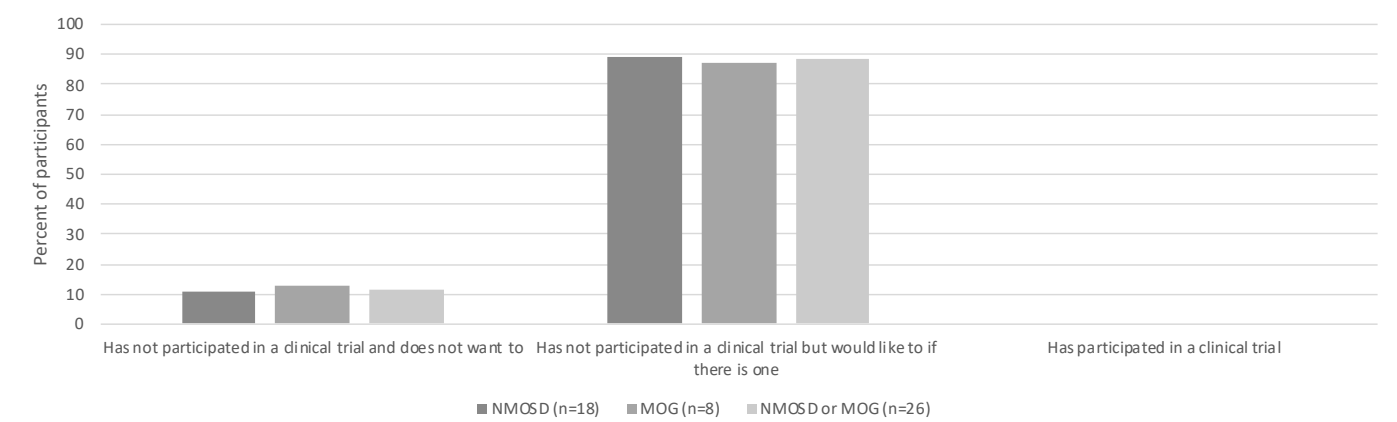


Figure 5.38: Clinical trial participation

Description of mild side effects

In the structured interview, participants were asked how they would describe the term ‘mild side effects’. The most common description of ‘mild side effects’ was providing a specific example (n=14, 77.78%), followed by those that can be self-managed and do not interfere with everyday life (n=5, (27.78%).

Participant provides a specific side effect as an example

The mild side effects are the spasms. You get heat intolerance. That's another side effect. I have heat intolerance. I find that once I heat up, it's very hard for me to cool down. Participant NMO_004

It varies and changes daily. The electric shocks and I call them tremors, my body tremors like it's inside. It feels like it's trembling the whole time. Constant severe burning through my whole right-hand side and left side. Pins and needles severe. I have a lot of, I can't think of the term, where it's like electric shock goes down my leg and I can't control my leg.

It just kicks out. Yes, a lot of, I think they call it banding or hugging, severe hugging right down my right-hand side. It feels like my whole right leg is being cast in plaster. Participant NMO_009

Mild side effects to me is something that you can take a pill for and it disappears or it eases, so nausea I can take an anti-nausea tablet and it alleviates it. Participant NMO_017

Participant describes mild side effects as those that can be self-managed and do not interfere with daily life

I don't know. If I could keep working or keep doing the things that I enjoy even with the side effects, I'd say they're kind of mild. Participant NMO_010

For me, mild is something that I can live with and I can deal with. Participant NMO_005

Mild is just, it's a little nibble, but you still get on with your day. Participant NMO_014

Table 5.33: Description of mild side effects

Description of mild side effects	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 function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant provides a specific side effect as an example	14	77.78	6	66.67	8	88.89	6	75.00	8	80.00	7	77.78	7	77.78
Participant describes mild side effects as those that can be self-managed and do not interfere with daily life	5	27.78	3	33.33	2	22.22	4	50.00	1	10.00	1	11.11	4	44.44

Description of mild side effects	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant provides a specific side effect as an example	14	77.78	8	80.00	6	75.00	5	83.33	9	75.00	5	71.43	9	81.82
Participant describes mild side effects as those that can be self-managed and do not interfere with daily life	5	27.78	2	20.00	3	37.50	1	16.67	4	33.33	3	42.86	2	18.18

Description of mild side effects	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 provides a specific side effect as an example	14	77.78	6	75.00	20	76.92	7	70.00	12	75.00	2	100.00	3	100.00	11	73.33
Participant describes mild side effects as those that can be self-managed and do not interfere with daily life	5	27.78	2	25.00	7	26.92	2	20.00	5	31.25	0	0.00	0	0.00	5	33.33

Table 5.34: Description of mild side effects (Subgroup variations)

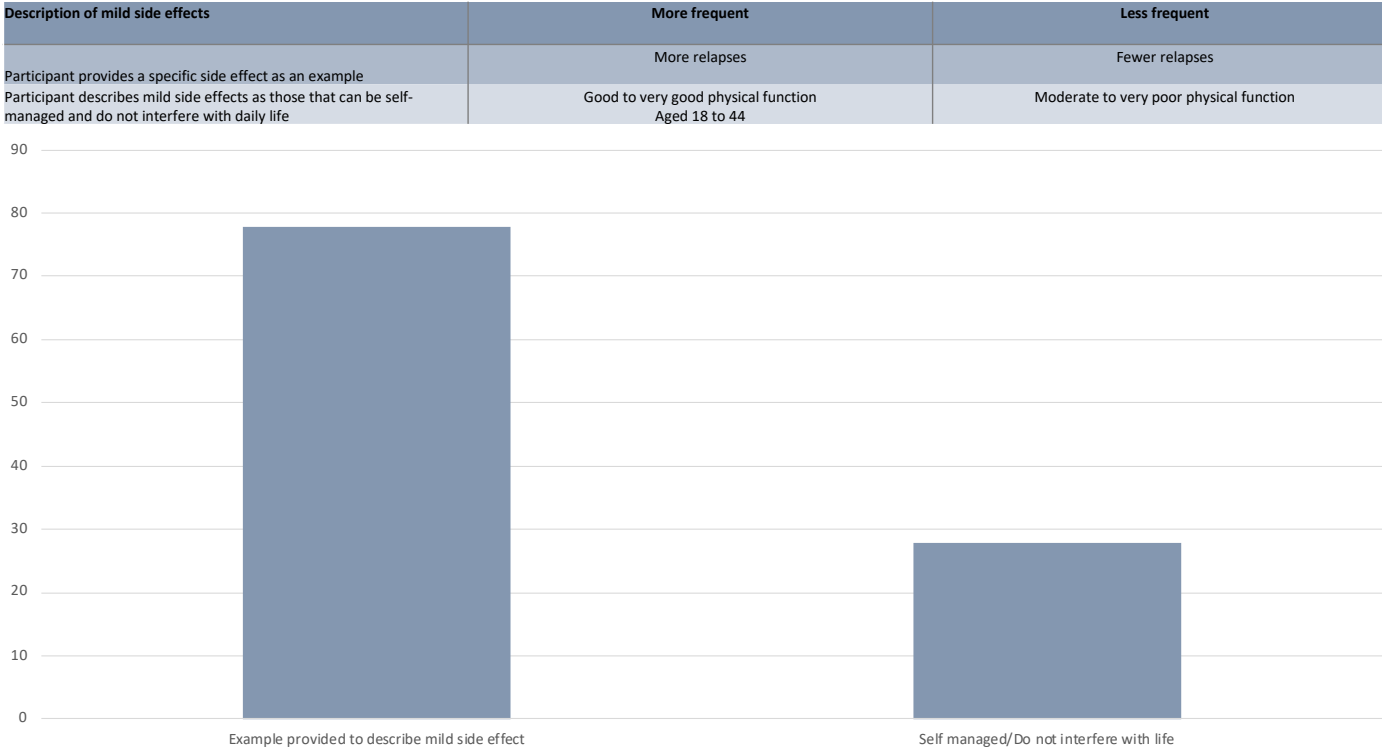


Figure 5.39: Description of mild side effects

Description of mild side effects: Specific side effects

There were five participants (27.78%) that described ‘mild side effects’ by giving the example of numbness/paresthesia and five participants (27.78%) who gave the example of neuropathic pain to describe mild side effects.

Participant describes mild side effects giving the specific example of numbness/paresthesia

He's got numbness in his leg. I would say that's probably a mild side effect. Participant NMOCA_007

No. That's okay. I wake up with a lot of numbness. I have hip pain. I have burning in my feet. Participant NMO_008

Pins and needles. If they are just locally that's a mild side effect as well as-- I think that would be the only-- Then there are some kind of more sharper pains every now and then but they are very seldom but they take place. I would put them also in the mild category. Participant NMOCA_003

Participant describes mild side effects giving the specific example of neuropathic pain

Right now I'm experiencing burning sensation. I guess for my first diagnosis, my residual side effect was actually quite minimal. It was just a bit of burning sensation here and there, not all the time on my back. From this recent relapse, the sensation is much bigger. I've got numbness on my right side of the torso. I have vibration in my legs. Those side effects, sometimes I felt like I'm not emptying- feeling constipated sometimes. It's just that kind of sensation. Participant NMO_001

I'll just get a little electrical storm going on. I can get things like-- I don't know what I've got-- I get banding all the time around my middle. It feels like I'm being squeezed. Sometimes it's okay, sometimes it's really bad, but sometimes it can just be mild. Participant NMO_011

For me, mild is sometimes or probably every day, say, I might get a quick sensation of a burning rash on the sides of my body, just in about a three or four-inch square and it will just be a little quick burn, and then it goes. On my left side, it's like I've still got the socks on and my left side's tight, and I get a little bit of just slight pain but nothing that bothers me at all. I just know that it's still there every day on my left leg. What else? Yes, that's my mild ones. Participant NMO_015

Participant describes mild side effects giving the specific example of fatigue/tiredness

Tiredness, I would say. A little bit tired always. Participant NMO_001

Yes, I get very fatigued from the medication. I get very fatigued, and I feel very run down for a few

days post. That's pretty much it really for mild, yes. Participant NMO_003

I don't know whether this has got to do with that or whether she's just being a teenager or what's happening there. She sleeps quite a lot. Participant NMOCA_006

Participant describes mild side effects giving the specific example of gastrointestinal distress

Those side effects, sometimes I felt like I'm not emptying- feeling constipated sometimes. It's just that kind of sensation. Participant NMO_001

Yes, maybe some confusion, mild pain at the sight, mild bloating, I guess, having these medications. Participant NMO_002

That's migraine or, yes, maybe just like stomach symptoms for a day, that's something that I find mild or like a little bit maybe of itchiness in the day of an antihistamine will just fix. Maybe that's how I would define mild. Yes. Participant MOG_006

Participant describes mild side effects giving the specific example of headaches/migraines

I look at IVIG and I think that gives me mild side effects, so it just gave me like a migraine for a few days and that was basically it. Participant MOG_006

She does get more headaches now. Participant NMOCA_004

For me, mild is something that I can live with and I can deal with. For example, like a headache, I have learned to live with my headaches. Participant NMO_005

Table 5.35: Description of mild side effects: Specific side effects

Description of mild side effects	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 function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes mild side effects giving the specific example of numbness/paresthesia	5	27.78	3	33.33	2	22.22	2	25.00	3	30.00	4	44.44	1	11.11
Participant describes mild side effects giving the specific example of neuropathic pain	5	27.78	3	33.33	2	22.22	2	25.00	3	30.00	3	33.33	2	22.22
Participant describes mild side effects giving the specific example of fatigue/tiredness	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	1	11.11	1	11.11
Participant describes mild side effects giving the specific example of gastrointestinal distress	2	11.11	1	11.11	1	11.11	2	25.00	0	0.00	1	11.11	1	11.11
Participant describes mild side effects giving the specific example of headaches/migraines	1	5.56	0	0.00	1	11.11	1	12.50	0	0.00	0	0.00	1	11.11

Description of mild side effects	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes mild side effects giving the specific example of numbness/paresthesia	5	27.78	3	30.00	2	25.00	2	33.33	3	25.00	2	28.57	3	27.27
Participant describes mild side effects giving the specific example of neuropathic pain	5	27.78	3	30.00	2	25.00	3	50.00	2	16.67	1	14.29	4	36.36
Participant describes mild side effects giving the specific example of fatigue/tiredness	2	11.11	1	10.00	1	12.50	0	0.00	2	16.67	2	28.57	0	0.00
Participant describes mild side effects giving the specific example of gastrointestinal distress	2	11.11	0	0.00	2	25.00	0	0.00	2	16.67	2	28.57	0	0.00
Participant describes mild side effects giving the specific example of headaches/migraines	1	5.56	0	0.00	1	12.50	0	0.00	1	8.33	1	14.29	0	0.00

Description of mild side effects	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 mild side effects giving the specific example of numbness/paresthesia	5	27.78	1	12.50	6	23.08	2	20.00	4	25.00	1	50.00	1	33.33	4	26.67
Participant describes mild side effects giving the specific example of neuropathic pain	5	27.78	0	0.00	5	19.23	0	0.00	4	25.00	1	50.00	2	66.67	3	20.00
Participant describes mild side effects giving the specific example of fatigue/tiredness	2	11.11	3	37.50	5	19.23	3	30.00	2	12.50	0	0.00	0	0.00	2	13.33
Participant describes mild side effects giving the specific example of gastrointestinal distress	2	11.11	3	37.50	5	19.23	0	00.00	2	12.50	0	0.00	0	0.00	2	13.33
Participant describes mild side effects giving the specific example of headaches/migraines	1	5.56	2	25.00	3	11.53	2	20.00	1	6.25	0	0.00	0	0.00	1	6.67

Table 5.36: Description of mild side effects: Specific side effects (Subgroup variations)

Description of mild side effects	More frequent	Less frequent
Participant describes mild side effects giving the specific example of numbness/paresthesia	Moderate to very poor physical function	Good to very good physical function
Participant describes mild side effects giving the specific example of neuropathic pain	Mid to low socioeconomic status	Higher socioeconomic status Aged 18 to 44

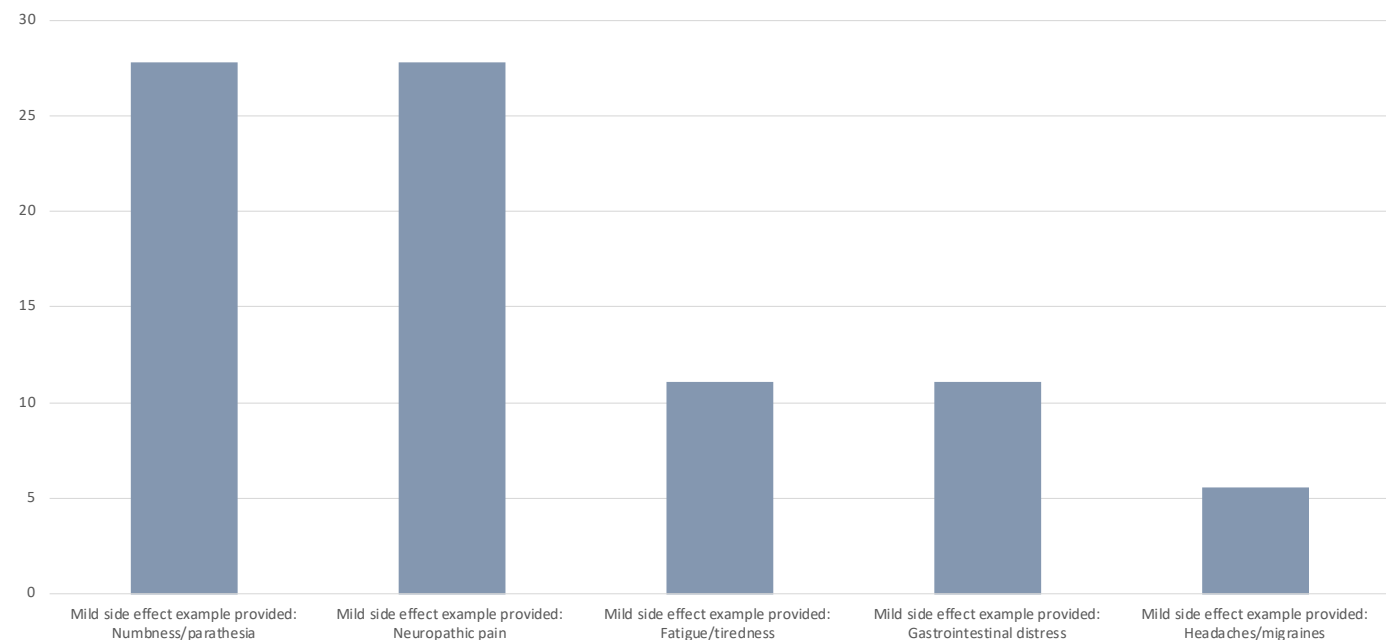


Figure 5.40: Description of mild side effects: Specific side effects

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of 'severe side effects' was providing a specific example to describe severe side effects (n=13, 72.22%).

Participant gives a specific example to describe severe side effects

The more severe ones, I guess, is the pain. The sudden onset of weakness where I can't speak and I can't move, that's serious. Participant NMO_004

I think the severe ones would be for me the weight gain because that affects me physically anyway. Then the cognitively, that was not good at all because it's hard when you don't feel right anyway, let alone a medication that seemed to be affecting me as well. Participant NMO_006

Severe side effects are the spasticity which occurs generally at night time. It feels like a massive cramp when my foot will turn round almost 90°, and I can't

stop it. I have to get out of bed and just slowly try and put weights on my leg. That can happen on a bad night I figured about 20 or 30 times happening during the night. Participant NMO_009

Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living

For me, severe would be something I can't live with. For example, I'm swelling up from my migraines, not being able to open my eyes in the sunlight, things like that. Like being really severely allergic to the sun on some of the medications where I'd go out, for example, to put the washing out, or for taking the washing down, and I'd be covered in a really painful rash. Participant NMO_005

Well, the opposite. The side effects would just be interfering, or if the side effects that are worse than what we were trying to manage, that would be severe but if I couldn't go about my normal day or enjoy things in life, then they would be pretty severe side effects. Participant NMO_010

It's where you're just incapable of living your normal life. Participant NMO_014

Table 5.37: Description of severe side effects

Description of severe side effects	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 function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant gives a specific example to describe severe side effects	13	72.22	5	55.56	8	88.89	6	75.00	7	70.00	7	77.78	6	66.67
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	4	22.22	2	22.22	2	22.22	3	37.50	1	10.00	0	0.00	4	44.44

Description of severe side effects	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant gives a specific example to describe severe side effects	13	72.22	7	70.00	6	75.00	2	66.67	11	73.33	6	85.71	7	63.64
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	4	22.22	2	20.00	2	25.00	1	33.33	3	20.00	2	28.57	2	18.18

Description of severe side effects	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 gives a specific example to describe severe side effects	13	72.22	6	75.00	19	73.08	7	70.00	11	68.75	2	100.00	4	66.67	9	75.00
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	4	22.22	0	0.00	4	15.38	1	10.00	4	25.00	0	0.00	2	33.33	2	16.67

Table 5.38: Description of severe side effects (Subgroup variations)

Description of severe side effects	More frequent		Less frequent	
	More relapses		Fewer relapses	
Participant gives a specific example to describe severe side effects	Aged 18 to 44			

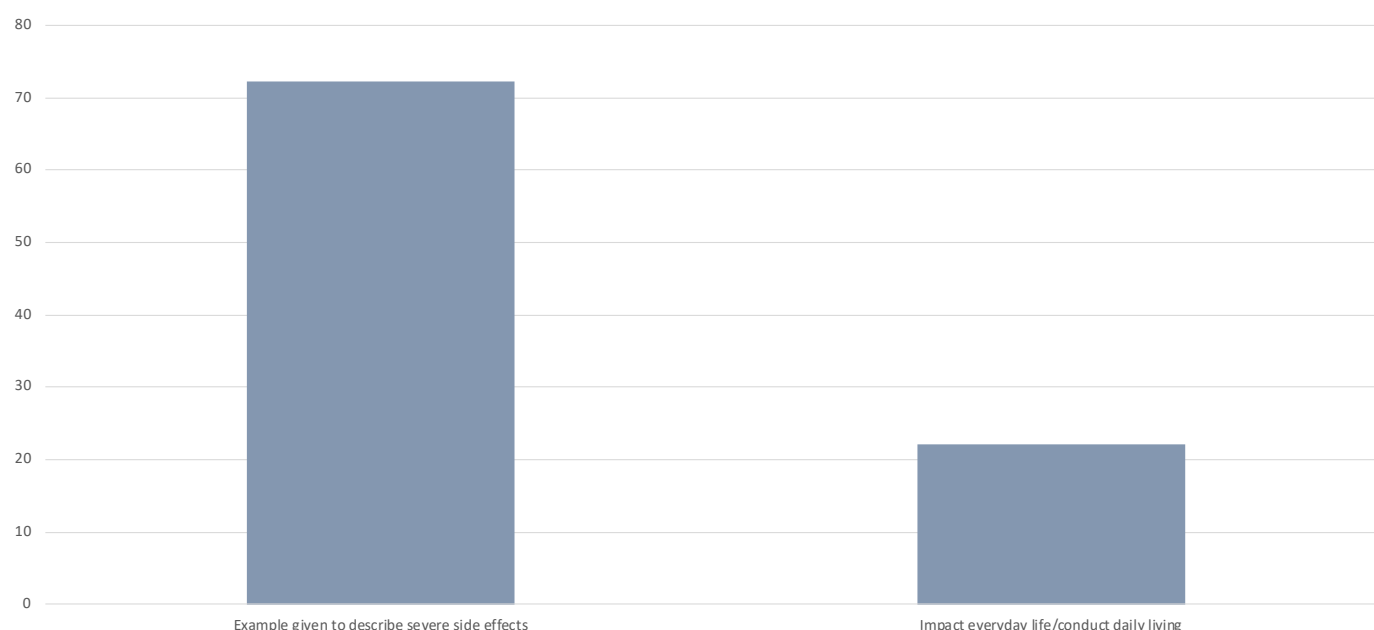


Figure 5.41: Description of severe side effects

Description of severe side effects: Specific side effects

The most common specific side effect given to describe 'severe side effects' was pain (n=6, 33.33%).

Participant describes severe side effects giving the specific example of pain

Pain. Pain will be the burning pain. To me, that's severe. Participant NMO_001

The more severe ones, I guess, is the pain. The sudden onset of weakness where I can't speak and I can't move, that's serious. Participant NMO_004

A severe side effect. He has constant pain. Participant NMOCA_007

Participant describes severe side effects giving the specific example of vision loss

When my vision disappears, usually from overheating, just moving around my body from one

side to the other and it's extremely painful. Participant NMO_011

I had double vision that I couldn't cope with. Not vomiting. I couldn't walk straight and severe headache. Did not cope well with any of that. Participant NMO_008

I think the loss of vision was obviously a very scary situation to have to deal with, and at the time, not knowing what was causing it, was even more daunting. Participant NMOCA_004

Participant describes severe side effects giving the specific example of fatigue/tiredness

Fatigue, just overwhelming exhaustion, and paralysis from the neck down, and the pain behind his eyes at different stages. Participant NMOCA_002

Yes. That pain. When I got the no sleeping and very severe stomach pain where you can't eat. That's what I really think severe is. Participant NMOCA_005

Table 5.39: Description of severe side effects: Specific side effects

Description of severe side effects: Specific side effect	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 function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes severe side effects giving the specific example of pain	6	33.33	3	33.33	3	33.33	3	37.50	3	30.00	5	55.56	1	11.11
Participant describes severe side effects giving the specific example of vision loss	3	16.67	0	0.00	3	33.33	1	12.50	2	20.00	2	22.22	1	11.11

Description of severe side effects: Specific side effect	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes severe side effects giving the specific example of pain	6	33.33	3	30.00	3	37.50	3	50.00	3	25.00	2	28.57	4	36.36
Participant describes severe side effects giving the specific example of vision loss	3	16.67	3	30.00	0	0.00	2	33.33	1	8.33	1	14.29	2	18.18

Description of severe side effects: Specific side effect	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 severe side effects giving the specific example of pain	6	33.33	2	25.00	8	30.77	3	30.00	5	31.25	1	50.00	1	33.33	5	33.33
Participant describes severe side effects giving the specific example of vision loss	3	16.67	1	12.50	4	15.38	5	50.00	3	18.75	0	0.00	1	33.33	2	13.33

Table 5.40: Description of severe side effects: Specific side effects (Subgroup variations)

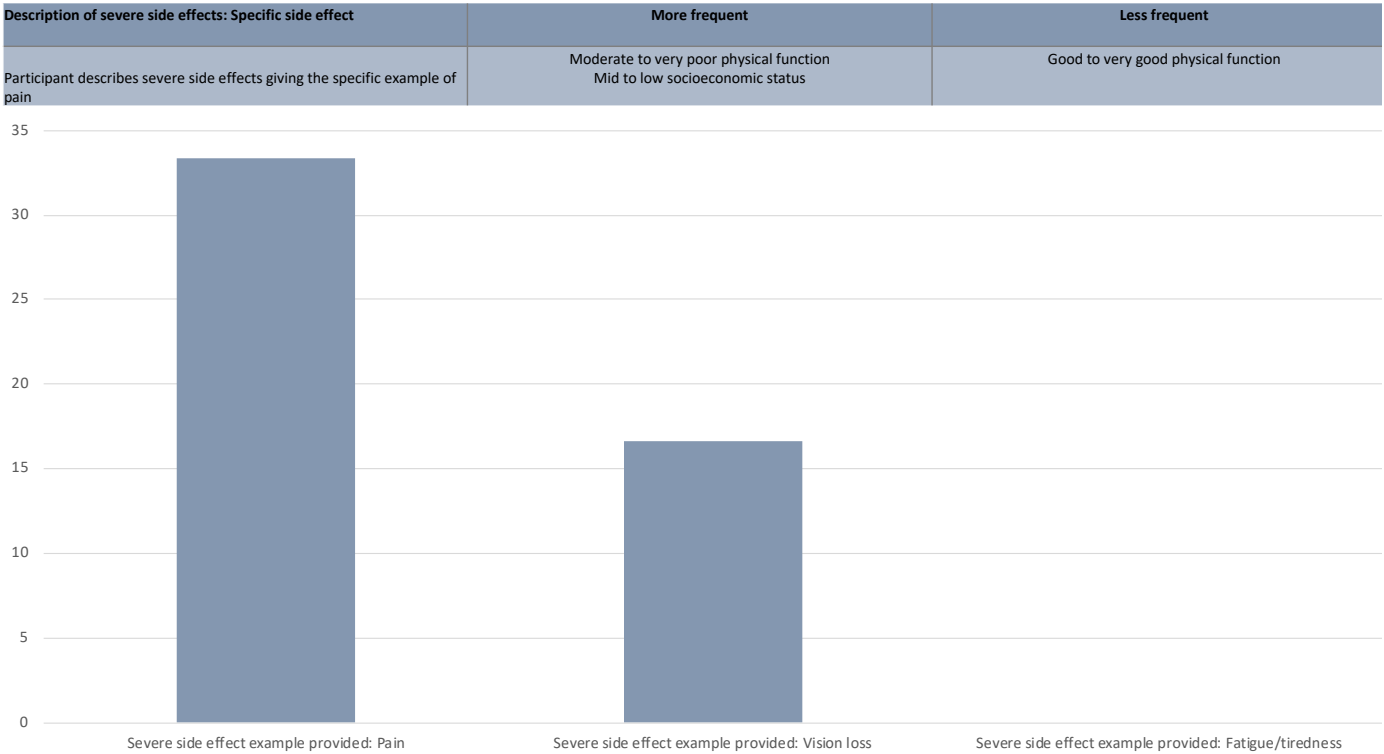


Figure 5.42: Description of severe side effects: Specific side effects

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common theme described was adhering to treatment as long as side effects are tolerable (n=5, 27.78%).

Participant describes adhering to treatment as long as side effects are tolerable

I don't, I always stick to it. Unless it makes me sick, I don't go off it. Participant NMO_007

I usually know fairly quickly. I've given it a few weeks, probably longer sometimes, unless it makes me really sick. For instance, I know that I can't use Lyrica. I've tried and it just does not agree with me. Participant NMO_011

I was given a new drug probably about four, five weeks ago. My neurologist said it was used for MS and it jumps the nerve. It helps you walk because I

have to walk with a walking stick. He said four weeks. It's quite an expensive drug. I tried it for two weeks, but I do have a very touchy stomach and nausea so that it was taking that too. With everything I had, plus the nausea, I thought I can't do it, so I had to go off of it type thing. Participant NMO_013

Participant describes not giving up on any treatment

At the moment I've been sticking to whatever medication was given. I have no problem taking it. Participant NMO_001

I've only been on one, which was Ocrevus for NMO. I feel like that's down to a lack of options. As far as I know, there's no specific drug on the PBS for NMO in Australia, so Ocrevus was I felt like the only option that I did have so kind of either that or nothing. Participant NMO_003

I haven't really had to do that because they put me on steroids in hospital and that helps. Participant NMO_008

Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed

For me, I would try as long as I can go. For example, with the mycophenolate, I was in contact with the doctor because my issues with my stomach and swelling up and things, and all that, they told me that I had to push through. I pushed through for about a month until I couldn't keep any food things down, so I ended up in hospital anyway because I had to get fluids and all of that, because I couldn't

keep anything down. Then that also led me into another relapse, but for that time, it was a month. I was also-- I probably would have wanted to quit after that earlier for two weeks or so, but the doctors told me to push through, so I tried to. Participant NMO_005

I probably, I'd wait until I then speak to the doctor and then if they believe that that-- I tell them what like I was telling them what was wrong with me with the gabapentin and that's when we decided to change. Participant NMO_006

I'd go by the neurologists. I trust what they say. Like I've said they've been fantastic. I haven't had any side effect to any drug so I wouldn't stop the medication. It's more in my mind, I'd rather just keep on what I'm doing if it keeps it stable, if that makes any sense. Participant NMO_009

Participant describes adhering to treatment for a specific amount of time 2 to 3 weeks

I usually know fairly quickly. I've given it a few weeks, probably longer sometimes, unless it makes me really sick. Participant NMO_011

Good question. I don't really know. I reckon it depends. With Rituximab, I gave it a pretty fair go. After a few weeks, I just couldn't handle being-- Yes. Participant NMOCA_005

The only times we've really given up on a medication is when he's had a reaction to the medication. That's usually anywhere from say three weeks after. Participant NMOCA_007

Table 5.41: Adherence to treatment

Adherence to treatment	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 function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes adhering to treatment as long as side effects are tolerable	5	27.78	3	33.33	2	22.22	2	25.00	3	30.00	3	33.33	2	22.22
Participant describes not giving up on any treatment	4	22.22	2	22.22	2	22.22	1	12.50	3	30.00	1	11.11	3	33.33
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	3	16.67	1	11.11	2	22.22	1	12.50	2	20.00	2	22.22	1	11.11

Adherence to treatment	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes adhering to treatment as long as side effects are tolerable	5	27.78	4	40.00	1	12.50	3	50.00	2	16.67	0	0.00	5	45.45
Participant describes not giving up on any treatment	4	22.22	2	20.00	2	25.00	1	16.67	3	25.00	2	28.57	2	18.18
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	3	16.67	2	20.00	1	12.50	1	16.67	2	16.67	2	28.57	1	9.09

Adherence to treatment	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 adhering to treatment as long as side effects are tolerable	5	27.78	2	25.00	7	26.92	2	20.00	4	25.00	1	50.00	1	33.33	4	26.67
Participant describes not giving up on any treatment	4	22.22	0	0.00	4	15.38	2	20.00	4	25.00	0	0.00	0	0.00	4	26.67
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	3	16.67	3	37.50	6	23.08	3	30.00	2	12.50	1	50.00	1	33.33	2	13.33

Table 5.42: Adherence to treatment (Subgroup variations)

Adherence to treatment	More frequent	Less frequent
Participant describes adhering to treatment as long as side effects are tolerable	Trade or high school Mid to low socioeconomic status Aged 45 or older	University Higher socioeconomic status Aged 18 to 44

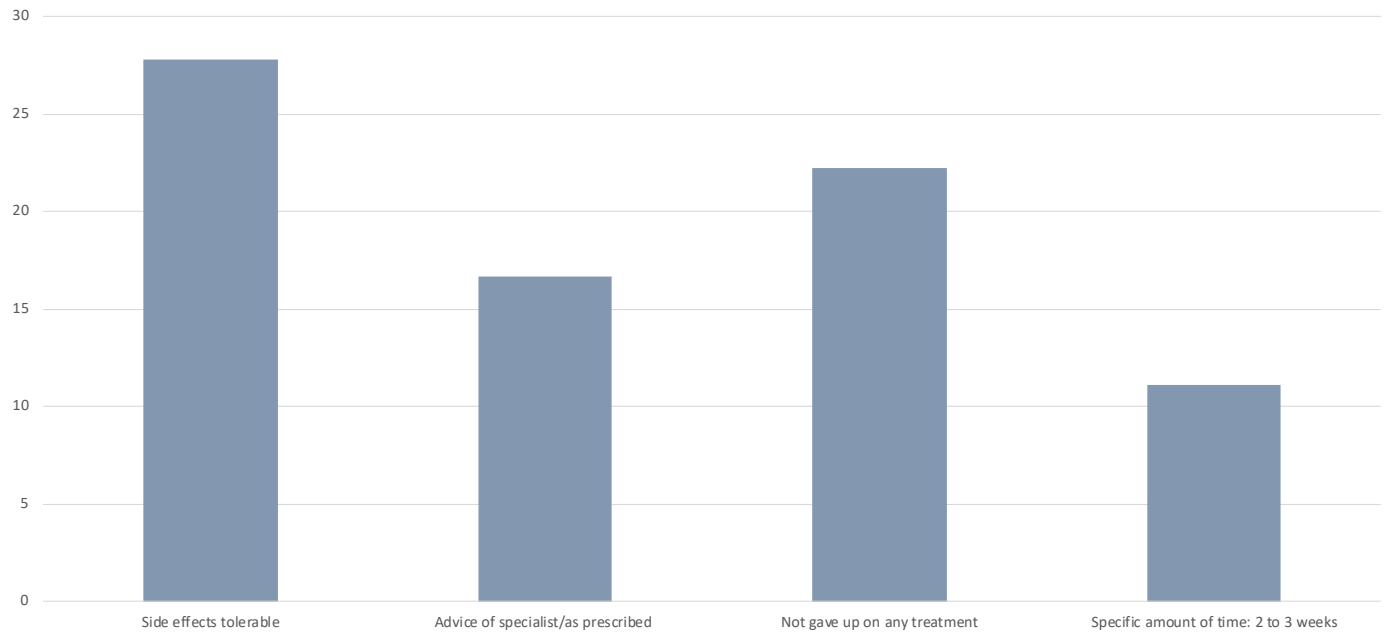


Figure 5.43: Adherence to treatment

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common response from six participants (33.33%) was needing to see a reduction in the symptoms of their condition. This was followed by needing to experience an improvement in pain levels (n=5, 27.78%).

Participant describes needing to see a reduction in symptoms of the condition to feel as though treatment is effective

No. I'm at that point in my diagnosis where I'm not really expecting any more improvement. I'd like my bladder to work better. Participant NMO_010

As I said to you, I feel like when I'm walking, my body's so tight, and it's quite depressing type thing that when you're walking around, you feel like

something's squeezing your legs and all that. If I can get a medication or sometimes if I take a Valium or Lyrica, it may help settle the nerve down. Then it's a lighter feeling. Participant NMO_013

It's just the reduction in what you've been prescribed to take it for. So looking into the muscle cramping and stuff like that. It seemed to work, but then it got worse, so I knew it wasn't working for me. Participant NMO_014

Participants reported needing to experience an improvement in pain levels

Well, I suppose being able to move without pain. Being less stiff. Medication treatments only do like pain and stuff and just stop the flares. Participant NMO_006

For me, it was mostly with my eyes. If there were, for example, side effects that were not mild side effects, I would deal with them if I could tell that they were helping my eyes where I wouldn't have pain in my eyes or no blurry vision. For me, if I start getting pain, I would first increase my steroids, but if that doesn't help, then it means the immunosuppressant doesn't work. Participant NMO_005

Yes. That's a reduction in the pains that I'm getting and things like that. Leading up to my infusion, I was starting to get more symptoms, but they seem to have eased since I've had it. Participant NMO_008

Participant describes needing to prevent relapses and/or worsening of their condition to feel as though treatment is effective

For me, for the treatment to work, I think rituximab whether it works then if I don't relapse then I will believe it worked. Otherwise, no. [laughs] I'm still yet to see what will happen next. Participant NMO_001

Basically, yes, when I'm not having a relapse, it's a good day. Participant NMO_003

Goodness. I don't know. With the Rituximab, it was just going from week to week and just hope you didn't relapse. We still don't know. At the moment

it's holding with Rituximab, but it's still-- And they say as well, it's a hope because there is no drug really out there so far that is just designed for NMO. Participant NMO_012

Participants reported needing to experience improved mobility

I think it was quite dramatic going from azathioprine to mycophenolate because I wasn't able to walk far at all, when I was contemplating life in a wheelchair just to get around to within a matter of a month later of being on mycophenolate, being able to walk 20 minutes. That was quite dramatic for me, the ability to walk. Participant NMO_004

As I said to you, I feel like when I'm walking, my body's so tight, and it's quite depressing type thing that when you're walking around, you feel like something's squeezing your legs and all that. If I can get a medication or sometimes if I take a Valium or Lyrica, it may help settle the nerve down. Then it's a lighter feeling. Participant NMO_013

Mobility, being able to move his arms and legs. Participant NMOCA_002

Participants reported needing to experience a reduction in vision issues

For me, it was mostly with my eyes. If there were, for example, side effects that were not mild side effects, I would deal with them if I could tell that they were helping my eyes where I wouldn't have pain in my eyes or no blurry vision. Participant NMO_005

See if something happens with my eye, I won't know until it really affects the part where I can see through because there's been times where I've had pain in my eye. There's been other times where I just lose the vision five days later then I lose the colour. So far we just keep praying every day. Participant NMO_012

Now, they giving her the IVig. I find this one is the better one. I know for the IVig helps her to get her vision back. For me, that's what I want from that. Participant NMOCA_006

Table 5.43: What needs to change to feel like treatment is working

What needs to change to feel like treatment is effective	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 function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes needing to see a reduction in symptoms of the condition to feel as though treatment is effective	6	33.33	4	44.44	2	22.22	3	37.50	3	30.00	2	22.22	4	44.44
Participants reported needing to experience an improvement in pain levels	5	27.78	1	11.11	4	44.44	1	12.50	4	40.00	3	33.33	2	22.22
Participant describes needing to prevent relapses and/or worsening of their condition to feel as though treatment is effective	4	22.22	2	22.22	2	22.22	1	12.50	3	30.00	1	11.11	3	33.33
Participants reported needing to experience improved mobility	4	22.22	2	22.22	2	22.22	1	12.50	3	30.00	4	44.44	0	0.00

What needs to change to feel like treatment is effective	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes needing to see a reduction in symptoms of the condition to feel as though treatment is effective	6	33.33	4	40.00	2	25.00	3	50.00	3	25.00	2	28.57	4	36.36
Participants reported needing to experience an improvement in pain levels	5	27.78	4	40.00	1	12.50	1	16.67	4	33.33	3	42.86	2	18.18
Participant describes needing to prevent relapses and/or worsening of their condition to feel as though treatment is effective	4	22.22	2	20.00	2	25.00	2	33.33	2	16.67	2	28.57	2	18.18
Participants reported needing to experience improved mobility	4	22.22	3	30.00	1	12.50	1	16.67	3	25.00	2	28.57	2	18.18

What needs to change to feel like treatment is effective	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 needing to see a reduction in symptoms of the condition to feel as though treatment is effective	6	33.33	2	25.00	8	30.77	3	30.00	5	31.25	1	50.00	2	66.67	4	26.67
Participants reported needing to experience an improvement in pain levels	5	27.78	2	25.00	7	26.92	1	10.00	5	31.25	0	0.00	0	0.00	5	33.33
Participant describes needing to prevent relapses and/or worsening of their condition to feel as though treatment is effective	4	22.22	3	37.50	7	26.92	3	30.00	4	25.00	0	0.00	1	33.33	3	20.00
Participants reported needing to experience improved mobility	4	22.22	0	0.00	4	15.38	1	10.00	4	25.00	0	0.00	0	0.00	4	26.67

Table 5.44: What needs to change to feel like treatment is working (Subgroup analysis)

What needs to change to feel like treatment is effective	More frequent	Less frequent
Participant describes needing to see a reduction in symptoms of the condition to feel as though treatment is effective	Fewer relapses Good to very good physical function Mid to low socioeconomic status	More relapses Moderate to very poor physical function
Participants reported needing to experience an improvement in pain levels	More relapses High to very high fear Trade or high school	Fewer relapses Low to moderate fear University Mid to low socioeconomic status

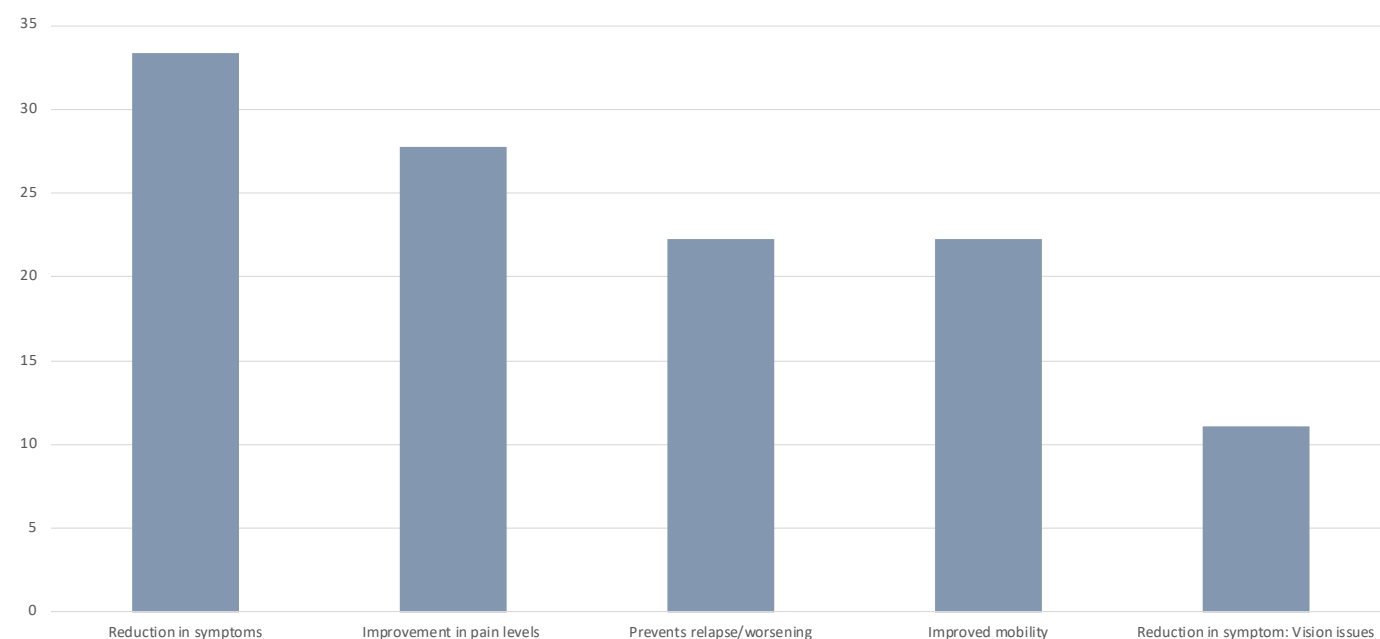


Figure 5.44: What needs to change to feel like treatment is working

Preference for treatment

Participants were asked to describe whether they would prefer treatment at home or in hospital. The most common response from nine participants (50.00%) was a preference for treatment at home. This was followed by a preference for treatment in hospital (n=5, 27.78%).

Participant describes a preference for treatment at home

I'd probably prefer it at home because I can't drive, so it would just be easier for me, because I won't have to-- My mum has to take a day off work, or my brother has to take a day off work, or my dad, to drive me. I guess it would be more just easier for everyone around me, but honestly, I don't really mind going into the hospital for an infusion. I guess it's just easier for the people around me. Participant NMO_005

I would prefer at home because it wouldn't interrupt my life as much. Participant NMO_010

At home, easy, because I'm in my own environment. I can just rest afterwards. Also because my immunity is reduced, it's also going to be safer for me to be at home rather than at the hospital. Participant NMO_011

Participant describes a preference for treatment in hospital

I think at the hospital because if anything happens, what you might not think will happen, you've got the medical people that know [laughs] compared to at home. Participant NMO_012

At hospital, because I go in there and do a fair bit. If there's any infusions, they look after me quite well. Participant NMO_013

I think the hospital I would prefer because I think you just don't know with the reactions. I think it's good, if it's a new treatment, just to see how it goes. Participant NMO_015

Participant describes a preference for neither

If a choice was available that would help, it wouldn't worry me whether it was at home or at a hospital. It's either way. Participant NMO_009

I don't particularly have a preferred. I suppose for the first couple of times I'd perhaps prefer the hospital, but if I had no side effects that happened with it I'd be happy to have it at home. Participant NMO_006

Today, I can't say which is the one I prefer because I don't know. Participant NMOCA_006

Table 5.45: Preference for treatment

Preference for treatment	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 function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes a preference for treatment at home	9	50.00	4	44.44	5	55.56	6	75.00	3	30.00	3	33.33	6	66.67
Participant describes a preference for treatment in hospital	5	27.78	3	33.33	2	22.22	1	12.50	4	40.00	3	33.33	2	22.22
Participant describes a preference for neither	3	16.67	1	11.11	2	22.22	1	12.50	2	20.00	2	22.22	1	11.11
Other/unsure/no response	1	5.56	1	11.11	0	0.00	0	0.00	1	10.00	1	11.11	0	0.00

Preference for treatment	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes a preference for treatment at home	9	50.00	5	50.00	4	50.00	3	50.00	6	50.00	4	57.14	5	45.45
Participant describes a preference for treatment in hospital	5	27.78	3	30.00	2	25.00	2	33.33	3	25.00	1	14.29	4	36.36
Participant describes a preference for neither	3	16.67	2	20.00	1	12.50	1	16.67	2	16.67	2	28.57	1	9.09
Other/unsure/no response	1	5.56	0	0.00	1	12.50	0	0.00	1	8.33	1	14.29	0	0.00

Preference for treatment	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 a preference for treatment at home	9	50.00	6	75.00	15	57.69	3	30.00	9	56.25	0	0.00	1	33.33	8	53.33
Participant describes a preference for treatment in hospital	5	27.78	2	25.00	7	26.92	3	30.00	4	25.00	1	50.00	1	33.33	4	26.67
Participant describes a preference for neither	3	16.67	0	0.00	3	11.54	2	20.00	2	12.50	1	50.00	1	33.33	2	13.33
Other/unsure/no response	1	5.56	0	0.00	1	3.85	2	20.00	1	6.25	0	0.00	0	0.00	1	6.67

Table 5.46: Preference for treatment (Subgroup variations)

Preference for treatment	More frequent	Less frequent
Participant describes a preference for treatment at home	Low to moderate fear Good to very good physical function	High to very high fear Moderate to very poor physical function
Participant describes a preference for treatment in hospital	High to very high fear Aged 45 or older	Low to moderate fear

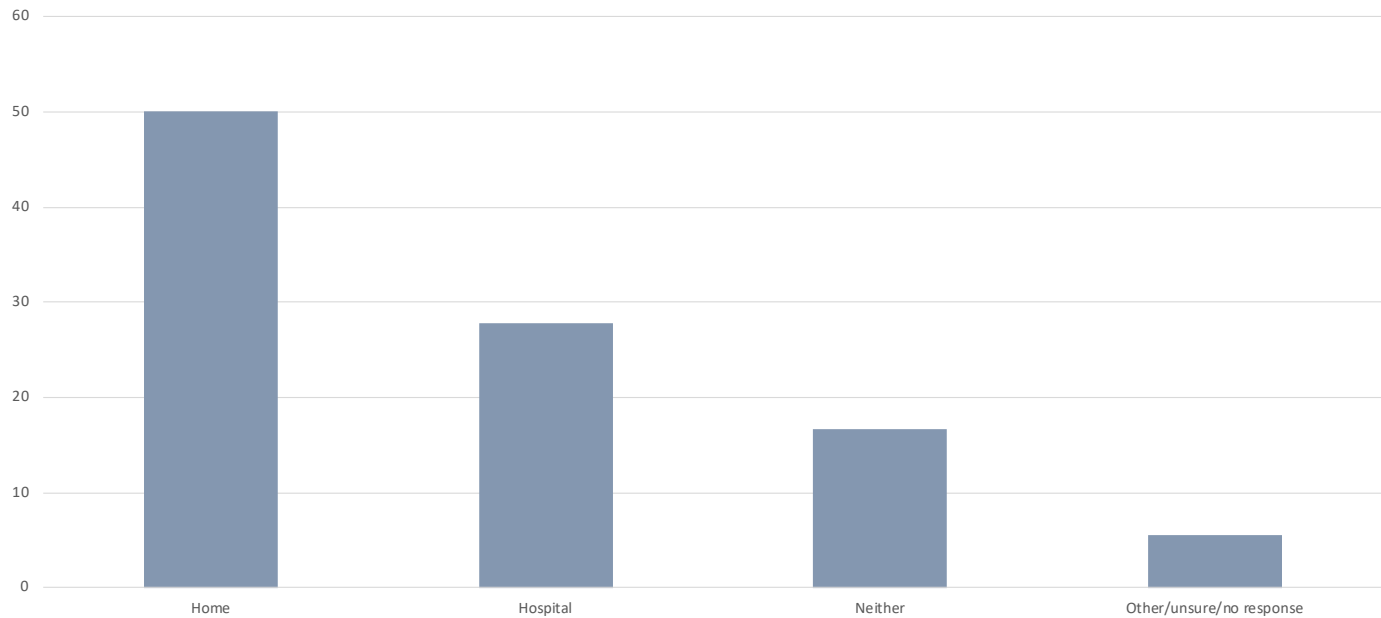


Figure 5.45: Preference for treatment

Preference for treatment: Rationale

There were eight participants (44.44%) who described preferring to have treatment at home because it is more convenient/comfortable and less interruption to daily life.

Participant describes a preference for medication at home because it is more convenient or comfortable and less interruption to everyday life.

I'd probably prefer it at home because I can't drive, so it would just be easier for me, because I won't have to-- My mum has to take a day off work, or my brother has to take a day off work, or my dad, to drive me. I guess it would be more just easier for everyone around me. Participant NMO_005

I would prefer at home because it wouldn't interrupt my life as much. Participant NMO_010

At home, of course, would obviously be very much more convenient in the infusion but my day for an infusion is long. Participant NMO_014

Participant describes a preference for treatment at home as they are safer from risk of infection or hospital acquired disease (including risk associated with being immunosuppressed)

I'd much prefer it at home. I don't want to be exposed more than I have to, to being immunosuppressed and just the convenience of having it in your own home is much, much better. Participant NMO_004

Obviously if you're at home, you're not surrounded by other people that are sick. Participant NMO_008

Particularly being immunosuppressed, that's a big factor. Participant NMOCA_007

Participant describes a preference for hospital in case something goes wrong

I think at the hospital because if anything happens, what you might not think will happen, you've got the medical people that know [laughs] compared to at home. Participant NMO_012

I think the hospital I would prefer because I think you just don't know with the reactions. I think it's good, if it's a new treatment, just to see how it

goes. Is there going to be any side effects? Just to keep that record. Participant NMO_015

I think definitely hospitals only because I am a very interesting case with side effects. I tend to always be the rare case. I think like if something did happen, at least doctors and staff would be there to-- and it'll be an infusion. I don't like pills. I'm very shocking at keeping up to date with taking pills. Yes. Definitely, at a hospital, nurses and doctors will be able to just immediately look after you if something happens. Participant NMOCA_005

Table 5.47: Preference for treatment: Rationale

Preference for treatment: Rationale	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 function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes a preference for medication at home because it is more convenient/comfortable and less interruption to everyday life	8	44.44	3	33.33	5	55.56	5	62.50	3	30.00	3	33.33	5	55.56
Participant describes a preference for treatment at home as they are safer from risk of infection or hospital acquired disease (including risk associated with being immunosuppressed)	4	22.22	2	22.22	2	22.22	3	37.50	1	10.00	2	22.22	2	22.22
Participant describes a preference for hospital in case something goes wrong	2	11.11	1	11.11	1	11.11	0	0.00	2	20.00	0	0.00	2	22.22

Preference for treatment: Rationale	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes a preference for medication at home because it is more convenient/comfortable and less interruption to everyday life	8	44.44	5	50.00	3	37.50	3	50.00	5	41.67	4	57.14	4	36.36
Participant describes a preference for treatment at home as they are safer from risk of infection or hospital acquired disease (including risk associated with being immunosuppressed)	4	22.22	2	20.00	2	25.00	1	16.67	3	25.00	0	0.00	4	36.36
Participant describes a preference for hospital in case something goes wrong	2	11.11	1	10.00	1	12.50	2	33.33	0	0.00	0	0.00	2	18.18

Preference for treatment: Rationale	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 a preference for medication at home because it is more convenient/comfortable and less interruption to everyday life	8	44.44	4	50.00	12	46.15	2	20.00	8	50.00	0	0.00	1	33.33	7	46.67
Participant describes a preference for treatment at home as they are safer from risk of infection or hospital acquired disease (including risk associated with being immunosuppressed)	4	22.22	2	25.00	6	23.08	1	10.00	4	25.00	0	0.00	1	33.33	3	20.00
Participant describes a preference for hospital in case something goes wrong	2	11.11	1	12.50	3	11.54	2	20.00	2	12.50	0	0.00	1	33.33	1	6.67

Table 5.47: Preference for treatment: Rationale (Subgroup variations)

Preference for treatment: Rationale	More frequent	Less frequent
Participant describes a preference for medication at home because it is more convenient/comfortable and less interruption to everyday life	<p><i>More relapses</i></p> <p><i>Low to moderate fear</i></p> <p><i>Good to very good physical function</i></p> <p><i>Aged 18 to 44</i></p>	<p><i>Fewer relapses</i></p> <p><i>High to very high fear</i></p> <p><i>Moderate to very poor physical function</i></p>

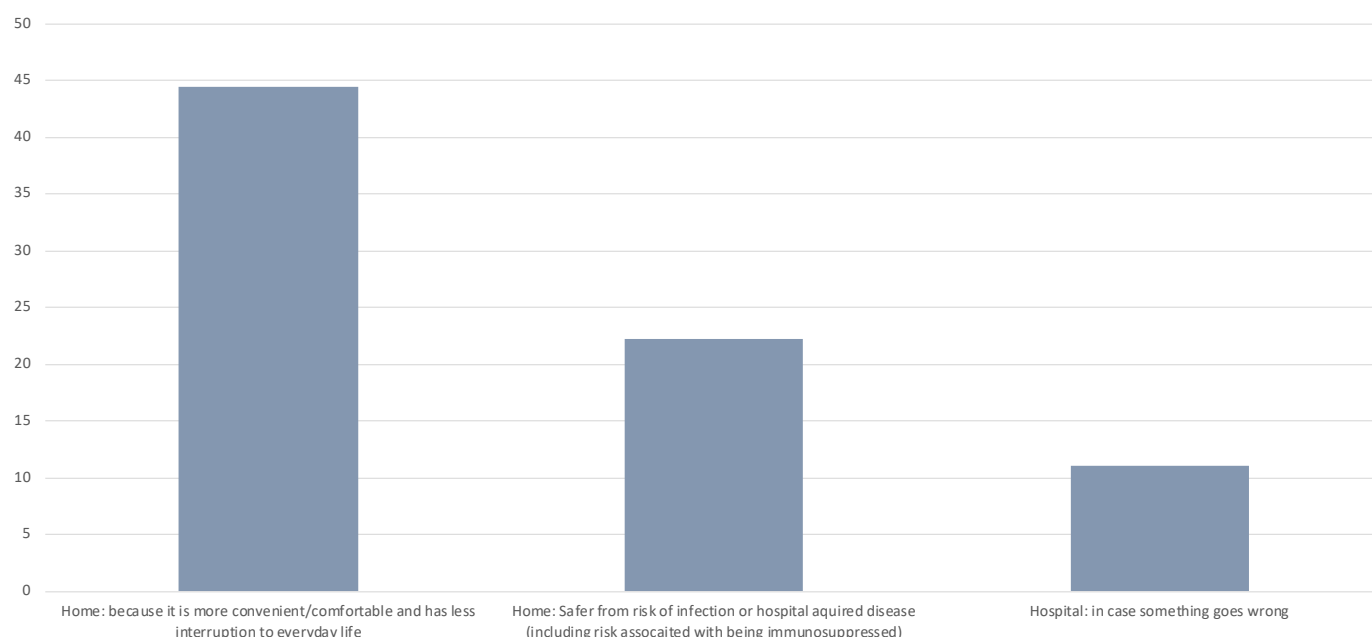


Figure 5.46: Preference for treatment: Rationale

Support needed for treatment at home

Participants were asked what support they would need to ease their anxiety about having treatment at home. There were three participants (16.67%) who described needing to be checked regularly by GP/Nurse at home.

Participant describes need to be checked regularly by GP/ Nurse at home

I think the only way is to have a nurse or a doctor around. Participant NMO_001

I don't know. I suppose a doctor here just in case. Participant NMO_007

If there was a nurse or whatever that was there with you just to make sure you were doing it correctly. Participant NMO_012

Participant describes needing training and education on how to administer treatment

I don't know about anxiety because before I would agree to it, I would've done all my research. [laughs] I have probably a good understanding of it and probably maybe some trials at hospital prior to doing it at home. Participant NMO_015

Just the training and support in just knowing that you are administering it correctly. I think as long as I knew what I needed to do I'd be comfortable enough. Participant MOG_008

Table 5.48: Support needed for treatment at home

Support needed for treatment at home	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 function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes need to be checked regularly by GP/ Nurse at home	3	16.67	1	11.11	2	22.22	1	12.50	2	20.00	3	33.33	1	11.11
Participant describes needing training and education on how to administer treatment	2	11.11	1	11.11	1	11.11	0	0.00	2	20.00	1	11.11	1	11.11

Support needed for treatment at home	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes need to be checked regularly by GP/ Nurse at home	3	16.67	2	20.00	1	12.50	1	16.67	2	16.67	1	14.29	2	18.18
Participant describes needing training and education on how to administer treatment	2	11.11	1	10.00	1	12.50	2	33.33	0	0.00	1	14.29	1	9.09

Support needed for treatment at home	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 need to be checked regularly by GP/ Nurse at home	3	16.67	0	0.00	3	11.54	3	30.00	2	12.50	1	50.00	1	33.33	2	13.33
Participant describes needing training and education on how to administer treatment	2	11.11	4	50.00	6	23.08	1	10.00	2	12.50	0	0.00	0	0.00	2	13.33

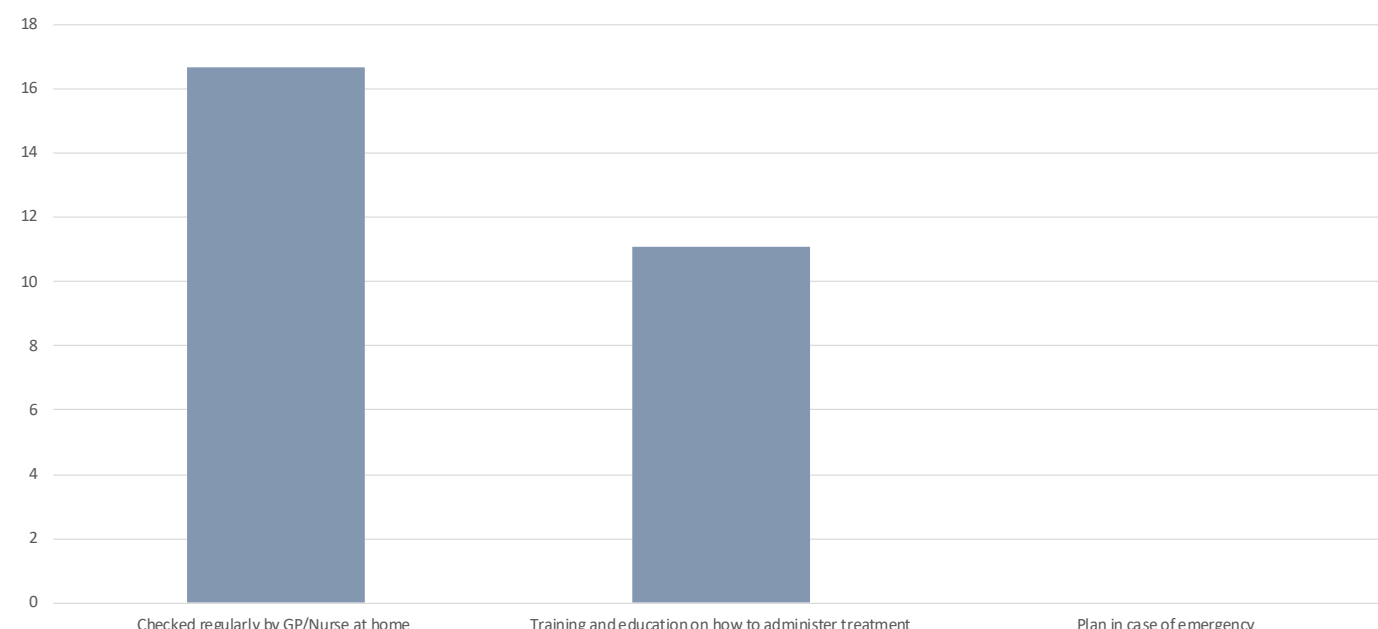


Figure 5.47: Support needed for treatment at home

Access to telehealth or remote access

Participants were whether they has access to telehealth or remote access. There were nine participants (55.56%) who described not having access to telehealth or remote access and eight participants (38.89%) described having access to telehealth or remote access.

Participant describes not having access to telehealth or remote access

No, don't think so. Participant NMO_012

No. I didn't need to. No. Participant NMO_017

No. I never did those. Participant NMOCA_005

Participant describes having access to telehealth or remote access

All of our conversations have been via phone really. Participant NMOCA_002

I did psychologically, a psychologist when COVID was on. I did telehealth and I also had two, three sessions with an OT who was a specialised OT for driving assessments because I needed to apply for hand controls. She did assessment on like a Zoom. NMO_006

Yes, we had like for her haematology and I think it was gynaecology because some of them are not often, like haematology is once a year, and then

because it was during the COVID, we had to have it on telehealth, those calls. Participant NMOCA_006

Table 5.49: Access to telehealth or remote access

Access to telehealth or remote access	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 function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes not having access to telehealth or remote access	10	55.56	4	44.44	6	66.67	3	37.50	7	70.00	5	55.56	5	55.56
Participant describes having access to telehealth or remote access	7	38.89	4	44.44	3	33.33	5	62.50	2	20.00	3	33.33	4	44.44
Other/unsure/no response	1	5.56	1	11.11	0	0.00	0	0.00	1	10.00	1	11.11	0	0.00

Access to telehealth or remote access	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes not having access to telehealth or remote access	10	55.56	7	70.00	3	37.50	3	50.00	7	58.33	2	28.57	8	72.73
Participant describes having access to telehealth or remote access	7	38.89	3	30.00	4	50.00	3	50.00	4	33.33	5	71.43	2	18.18
Other/unsure/no response	1	5.56	0	0.00	1	12.50	0	0.00	1	8.33	1	14.29	0	0.00

Access to telehealth or remote access	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 not having access to telehealth or remote access	10	55.56	2	25.00	12	46.15	6	60.00	9	56.25	1	50.00	2	66.67	8	53.33
Participant describes having access to telehealth or remote access	7	38.89	6	75.00	13	50.00	3	30.00	6	37.50	1	50.00	1	33.33	6	40.00
Other/unsure/no response	1	5.56	0	0.00	1	3.85	1	10.00	1	6.25	0	0.00	0	0.00	1	6.67

Table 5.50: Access to telehealth or remote access

Access to telehealth or remote access	More frequent	Less frequent
Participant describes not having access to telehealth or remote access	More relapses High to very high fear Trade or high school Aged 45 or older	Fewer relapses Low to moderate fear University Aged 18 to 44
Participant describes having access to telehealth or remote access	Low to moderate fear University Mid to low socioeconomic status Aged 18 to 44	High to very high fear Aged 45 or older

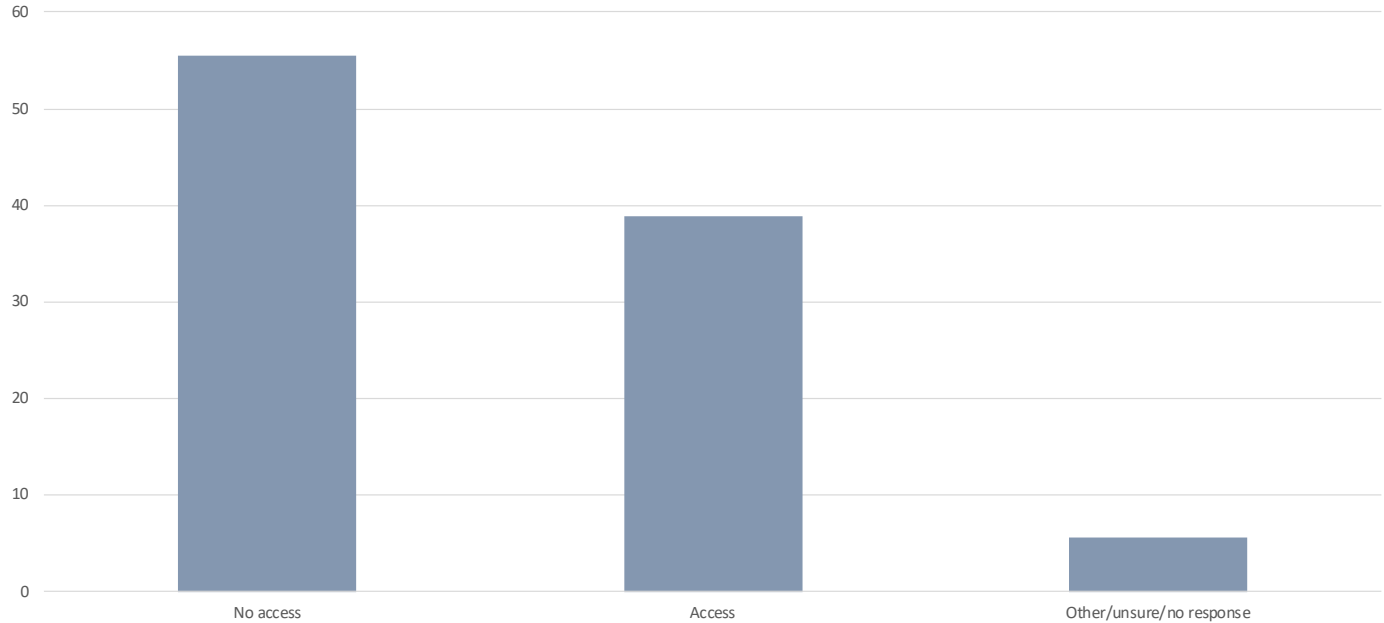


Figure 5.48: Access to telehealth or remote access

Access to telehealth or remote access: Experience

There were nine participants (55.56%) who did not receive care through telehealth or remote access and so gave no opinion. This was followed by five

participants (22.22%) who were pleased with their experience of telehealth or remote access.

Participant did not receive care through telehealth or remote access (no opinion given)

No. Participant NMO_015

No. I didn't need to. No. Participant NMO_017

No. Participant NMOCA_003

Participant was pleased with their experience with telehealth or remote access

Oh, very good and very easy. Convenient and easy. Participant NMO_001

Yes, that's been really good. The first time I did it, it was a little bit difficult, sort of getting used to logging in and all that sort of stuff, but it was fine. Participant NMO_009

Just recently, I did a lot of physio through telehealth with COVID. I've had specialist appointments, which I had to go. It's good. No problems. Participant NMO_010

Table 5.51: Access to telehealth or remote access: Experience

Access to telehealth or remote access	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 function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant did not receive care through telehealth or remote access (no opinion given)	10	55.56	4	44.44	6	66.67	3	37.50	7	70.00	5	55.56	5	55.56
Participant was pleased with their experience with telehealth or remote access	4	22.22	3	33.33	1	11.11	3	37.50	1	10.00	2	22.22	2	22.22

Access to telehealth or remote access	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant did not receive care through telehealth or remote access (no opinion given)	10	55.56	7	70.00	3	37.50	3	50.00	7	58.33	2	28.57	8	72.73
Participant was pleased with their experience with telehealth or remote access	4	22.22	1	10.00	3	37.50	1	16.67	3	25.00	3	42.86	1	9.09

Access to telehealth or remote access	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 did not receive care through telehealth or remote access (no opinion given)	10	55.56	2	25.00	12	46.15	3	30.00	9	56.25	1	50.00	2	66.67	8	53.33
Participant was pleased with their experience with telehealth or remote access	4	22.22	5	62.50	9	34.62	4	40.00	3	18.75	1	50.00	1	33.33	3	20.00

Table 5.52: Access to telehealth or remote access: Experience

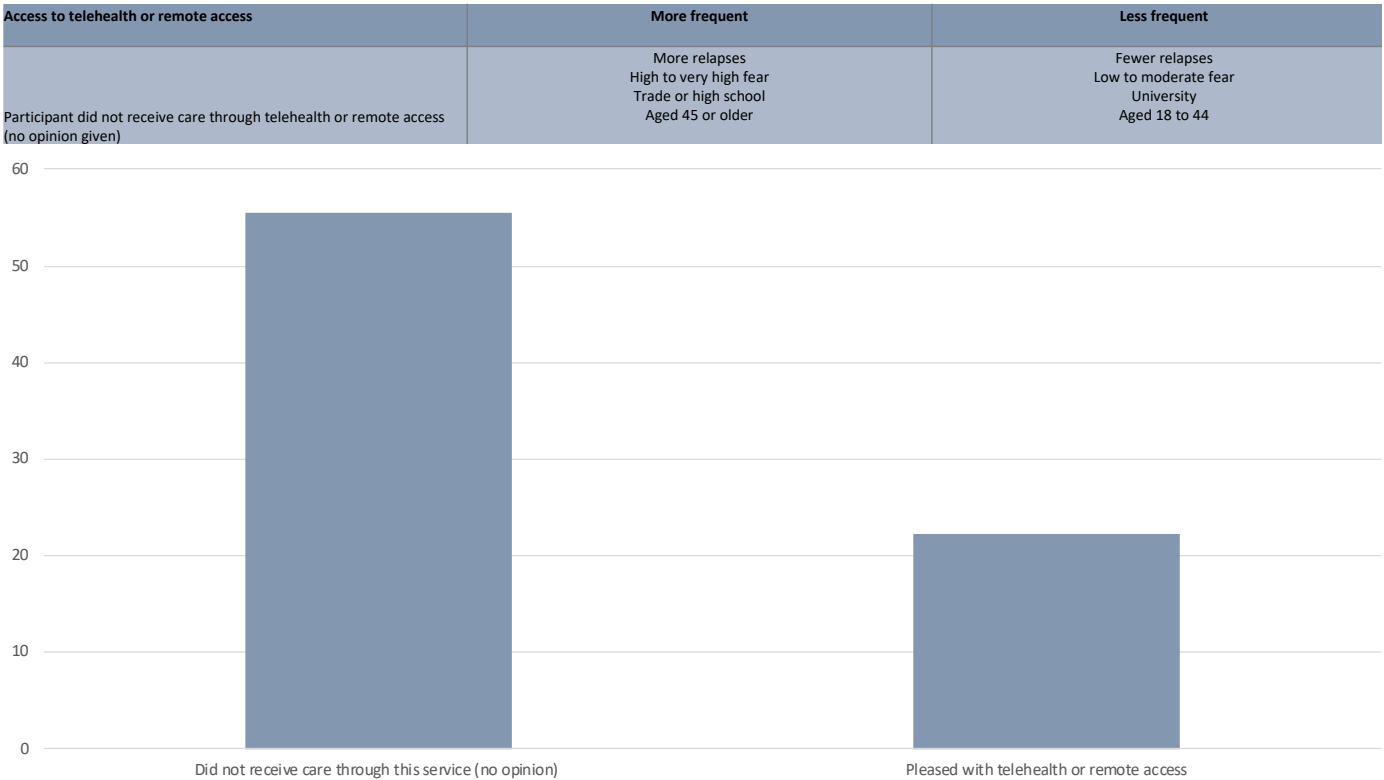


Figure 5.49: Access to telehealth or remote access: Experience

What would it mean if treatment worked

Participants were asked what it would mean for them if treatment worked. The most common response from six participants (33.33%) was allowing them to engage more with social activities and family life.

Participant described treatment allowing them to engage more with social activities and family life

If I didn't have fatigue, I would probably be able to spend a lot more energy with my children. There's some days where I just come home from LOCATION and go straight to bed at like 4:00 O'clock, and my partner kind of has to pick up the slack a lot just because I don't have the energy. Participant NMO_003

It would then help with the fatigue because I wouldn't be as tired and fatigued from doing the smallest simplest thing. Then I'd be able to spend more time with my grandchildren without being completely exhausted and not feeling like I'm a capable Nana and being able to look after your own grandchildren. Being able to go out with my husband without having to plan that I go out in the morning and not the afternoon because I get too tired by the afternoon. Participant NMO_006

He could participate in a lot more things, a lot more family things. We could do a lot more. Participant NMOCA_007

Participant describes treatment allowing them to do everyday activities/ return to normal life

I'm obviously retired. The treatment is that I have a cleaner now coming. I can only virtually do something for an hour or so, and then I have to stop. Then start again and stop, to relax the body down. If I'm doing something, like doing a little bit of housework or whatever, I virtually have to do a little bit and then my body all plays up and the nerve sensation, everything just goes out of whack. I used to play golf, do all those things, which-- That's what I'm trying to say. Yes, it'd be lovely if I could be normal again, but it's not going to happen because my spine is damaged, and whatever I do, even the pain doctor said, "may work, may not

work". In all my trials and different things that's happening, they give me that option of, "We can try it. It may work for you, or it may not work for you." They can't say to me, "This is a super drug that's going to work." Participant NMO_013

Just live my normal life. Participant NMO_014

Probably not lean on my husband so heavily for chores around the house. We have our grandchildren every Friday. NAME GRANDSON's four now the youngest, so it's not too bad. You feel you're not pulling your weight. Neither of us is getting any younger. That's probably the thing for me, it's being out to do my share of the workload in a timely and appropriate manner, not having to do a job over three days, but actually just doing it an hour. Participant MOG_001

Participant describes treatment allowing them to have an increased mobility/independence

That I can still see or I can still walk. It's just those things. I'm grateful for that I can still see something. As well as still walk and be able to pick up things. Participant NMO_012

I'm able to go outside and walk in the dark and actually see on the floor and see the waves crashing in the water. I couldn't do that when I was on rituximab and stuff. Yes. That's something that I see is a massive improvement. Yes. It made me really look forward to every single day so it's definitely something I want to stick to. Participant NMOCA_005

The ability for treatment to give my life back to me. Even though I have a fantastic life now, then I've made it so that way, it would give me stamina, it would give me the ability to walk and hike for much longer. Participant NMO_004

Participant describes treatment allowing them to return to work

Well, obviously, I haven't been able to work. I can't work because I don't have the stamina anymore. Even one phone conversation will exhaust me. The ability for treatment to give my life back to me. Participant NMO_004

Being able to go back to work, that sort of thing.
Participant NMOCA_002

That I can still see or I can still walk. It's just those things. I'm grateful for that I can still see something. As well as still walk and be able to pick up things. Participant NMO_012

Participant describes treatment improving their vision

Table 5.53: What would it mean if treatment worked

What would it mean if treatment worked	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 function	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant described treatment allowing them to engage more with social activities and family life	6	33.33	2	22.22	4	44.44	3	37.50	3	30.00	3	33.33	3	33.33
Participant describes treatment allowing them to do everyday activities/ return to normal life	4	22.22	2	22.22	2	22.22	1	12.50	3	30.00	3	33.33	1	11.11
Participant describes treatment allowing them to have an increased mobility/independence	3	16.67	2	22.22	1	11.11	1	12.50	2	20.00	2	22.22	1	11.11
Participant describes treatment allowing them to return to work	2	11.11	2	22.22	0	0.00	2	25.00	0	0.00	1	11.11	1	11.11
Participant describes treatment improving their vision	1	5.56	0	0.00	1	11.11	0	0.00	1	10.00	0	0.00	1	11.11

What would it mean if treatment worked	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or older	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant described treatment allowing them to engage more with social activities and family life	6	33.33	4	40.00	2	25.00	1	16.67	5	41.67	3	42.86	3	27.27
Participant describes treatment allowing them to do everyday activities/ return to normal life	4	22.22	4	40.00	0	0.00	2	33.33	2	16.67	1	14.29	3	27.27
Participant describes treatment allowing them to have an increased mobility/independence	3	16.67	2	20.00	1	12.50	2	33.33	1	8.33	0	0.00	3	27.27
Participant describes treatment allowing them to return to work	2	11.11	0	0.00	2	25.00	0	0.00	2	16.67	1	14.29	1	9.09
Participant describes treatment improving their vision	1	5.56	1	10.00	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09

What would it mean if treatment worked	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 described treatment allowing them to engage more with social activities and family life	6	33.33	3	37.50	9	34.62	4	40.00	6	37.50	0	0.00	1	33.33	5	33.33
Participant describes treatment allowing them to do everyday activities/ return to normal life	4	22.22	5	62.50	9	34.62	3	30.00	3	18.75	1	50.00	0	0.00	4	26.67
Participant describes treatment allowing them to have an increased mobility/independence	3	16.67	3	37.50	6	23.08	2	20.00	2	12.50	1	50.00	2	66.67	1	6.67
Participant describes treatment allowing them to return to work	2	11.11	2	25.00	4	15.38	2	20.00	2	12.50	0	0.00	0	0.00	2	13.33
Participant describes treatment improving their vision	1	5.56	3	37.50	4	15.38	1	10.00	1	6.25	0	0.00	1	33.33	0	0.00

Table 5.54: What would it mean if treatment worked (Subgroup variations)

What would it mean if treatment worked	More frequent	Less frequent
Participant described treatment allowing them to engage more with social activities and family life	More relapses	Fewer relapses Mid to low socioeconomic status

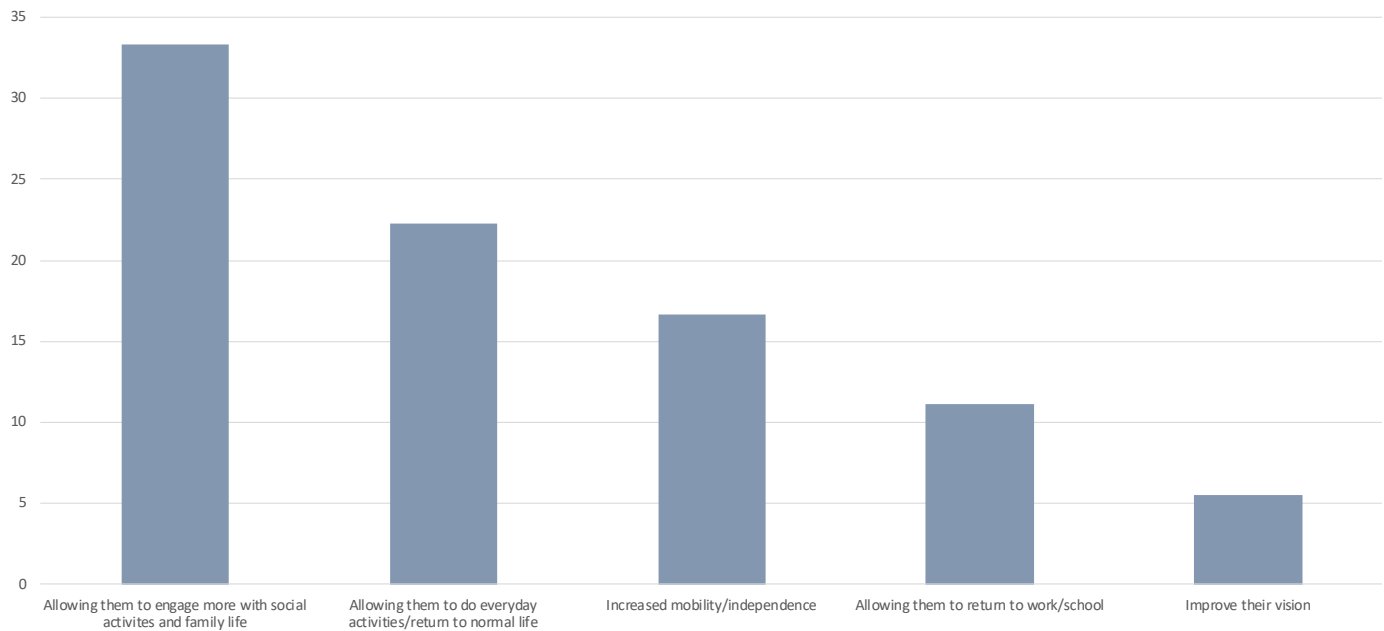


Figure 5.50: What would it mean if treatment worked