CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Personal Experience, Expectations and Knowledge (PEEK)

People diagnosed with and carers of people diagnosed with:

NMOSD

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PEEK study process information

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Number of participants	36 (18 with NMOSD, 8 with MOG, and 10 family and carers)
Average interview time	56 minutes 45 seconds

Contents

Summary of results

Executive summary

There were 18 participants with NMOSD, eight participants with MOG and 10 people who cared for people with NMOSD or MOG, in the study from across Australia. This characterisation of the study will focus on participants with NMOSD. The majority of participants lived in major cities, they lived in all levels of economic advantage. Most of the of participants identified as Caucasian or white, and were aged mostly between 45 and 64. Under half of the participants had completed some university, and less than a third were employed either full time or part time. Less than a third of participants were carers to family members or spouses.

Participants in this PEEK study most commonly had between two and four relapses, and were diagnosed after they turned 40. This patient population was also characterised by comorbidities with an average of four other conditions in addition to NMOSD. More than half of the participants had chronic pain, sleep problems, or depression.

This is a patient population that sought medical attention relatively soon after noticing symptoms The most common symptoms before an NMOSD diagnosis were loss of clear vision, eye pain, muscle spasms, and sensory loss, causing a poor quality of life. Visual problems was the symptom that most often led to a diagnosis.

On average, this group had six diagnostic tests for their condition, they were diagnosed by a neurologist at hospital. They were most commonly diagnosed after being admitted to the emergency department or hospital. They didn't have enough emotional support or enough information at diagnosis. This is a cohort that did not have conversations about biomarker, genomic, or gene testing, but were able to recall having had this type of test.

This is a study cohort that knew nothing or very little about their condition at diagnosis. They commonly associated the condition with multiple sclerosis and poor prognosis, often describing their prognosis in relation to the long-term permanent effects they have suffered from it.

This is a patient population that mostly had discussions about multiple treatment options, some participated in the decision-making process while others did not. The most common specific treatment discussed was rituximab.

This is a study cohort that considered the side effects, efficacy and costs when making decisions about treatment. The participants felt that the way they made decisions had changed over time because they had become more informed or assertive.

When asked about their personal goals of treatment or care, participants wanted to maintain their condition, and prevent relapses.

This is a group who felt that throughout their experience, they were treated with respect , with the exception of one or two occasions. They were all cared for by a neurologist.

This is a cohort that had private health insurance that were often treated as public patients in public hospitals. They had no problems with paying for healthcare appointments, filling prescriptions, paying for basic essentials. The monthly out of pocket spending for NMOSD wasn't usually a significant burden.

Participants in this study had to quit their job, though carers and family did not have to change employment status. The loss of income due to NMOSD was a burden on many participants.

All participants had been treated with high dose steroids, while this was found to be effective, the quality of life was low. The most common immunosuppressant taken was rituximab, about half had no side effects from rituximab, participants found this treatment effective.

There were very few conversations about clinical trials, however, they would take part in a clinical trial if there was a suitable one for them.

This is a patient population that described mild side effects using examples like numbness or paresthesia, and neuropathic pain. They also described severe side effects using examples, such as pain, or vision loss.

Within this patient population, participants adhered to a treatment plan as long as side effects were tolerable. This is a study cohort that needed to see a reduction in a specific symptoms in order to feel that treatment is working as well as needed to see an improvements in pain levels.

Participants preferred to have treatment at home rather than in hospital because it was more comfortable and convenient, with less interruption to daily life. Participants in this study would need to be checked regularly by a GP or nurse at home if they were having treatment at home to ease their anxiety.

This study cohort largely had some access to allied health services the most common being occupational therapists, physiotherapists, and psychologists. They found that services from allied health were generally effective.

Almost all participants made lifestyle changes to help manage their NMOSD, they usually exercised or made diet changes. They also tried complementary therapies to help manage their condition.

This participant population largely did not have access to telehealth services. Access was usually due to COVID-19, and those who used telehealth were pleased with their experience.

Within this patient population, it was most commonly felt that if treatment worked it would allow them to engage more with social activities and family life.

Participants in this study had good knowledge about their condition, were good at recognizing and managing symptoms, were excellent at adhering to treatment, and were average at coping with their condition,

Participants weren't given a lot of information about NMOSD. They were mostly given information treatment options, and disease management. Participants searched for information about many aspects of NMOSD including disease management, disease causes, treatment options, complementary therapies, and physical activity. This is a group who accessed information from non-profit, charity or patient organisations most often.

This is a patient population that accessed information through the internet, Facebook and the Guthy-Jackson Foundation. There was no information that wasn't helpful, but they found other people's experiences especially helpful.

This is a group that preferred to get their information online, talking to someone, or a mixture of both. They generally felt most receptive to information from the beginning, at diagnosis, or wanted to wait a bit after diagnosis to be given information.

Participants had a negative experience of communication when the healthcare profession had limited knowledge about NMOSD. They had positive experience of communication when conversations with healthcare professionals were two-way, supportive and comprehensive.

The participants in this study experienced good quality of care, and average coordination of care. They had an average ability to navigate the healthcare system, and experienced poor communication from healthcare professionals.

This is a patient population that most commonly did not receive care and support, though when they did, it was mainly through domestic services, for transport and from a hospital or clinical setting.

This is a patient population that experienced a negative impact on quality of life generally due to emotional strain on family/change in relationship dynamics and reduced capacity for physical activity. Emotional strain on family and changes in relationship dynamics had a negative impact on quality of life, as did the reduced capacity for physical activity

This is a study cohort that experienced at least some impact on their mental health and to maintain their mental health they exercised or used mindfulness techniques and meditation.

Within this patient population, participants described the importance of being understanding of their limitations, and practising self-care in order to maintain their general health.

This cohort most commonly felt there was a negative impact on their relationships due to having difficulties socialising.

This patient population felt their condition was a burden on their family, usually it was because of the extra household duties or responsibilities their family had to take on, and being taken to appointments.

Most participants felt there was some cost burden which was primarily in relation to time off work, and the cost of treatments.

The participants in this PEEK study had high levels of anxiety in relation to their condition, and overall, NMOSD had a negative impact on quality of life.

Participants would like future treatments to have fewer or less intense side effects, for there to be more options to treat NMOSD, and more affordable treatments.

This is a study cohort that would like more information that is specific to NMOSD, and information about where to find services.

Participants in this study would like future communication to be more transparent and for healthcare professionals to be more forthcoming with information. They would like specialist clinics or services for NMOSD where they can talk to professionals, either in person, online or by telephone.

This patient population was grateful for healthcare staff, the entire health system, and low cost or free medical care through the government.

It was important for this cohort to control weakness or paralysis of arms and legs, loss of clear vision, and loss of bowel or bladder control. Participants in this study would consider taking a treatment for more than ten years if quality of life is improved with no cure.

Participants in this study valued knowing the safety of medication, and side effects when making treatment decisions, and thought that the government should consider the quality of life of patients when making decisions that impact treatment and care.

The message to decision-makers given by participants in this study was to invest in new treatments and make them more accessible. They would like more NMOSD research, and better access to support and care.

This is a patient population that wished they had known what to expect from their condition, the treatments available to prevent attacks, and they wish they had known to ask more questions and advocate for themselves.

Most participants in this cohort would not change their care and treatment primarily because they were satisfied with the care they received, though there were some that would have liked better communication and continuity of care.

Section 1 Introduction and methodology

About this condition

Neuromyelitis optica spectrum disorder (NMOSD) is an autoimmune disease of the brain and spinal cord, characterised by optic neuritis (inflammation of the optic nerve) and myelitis (inflammation of the spinal cord)[1,2].

Although NMOSD can affect men and women of all ages and ethnicities, middle-aged and elderly women are most commonly affected[5]. The average age of onset is 40 years of age[6], and NMOSD is more common in non-white ethnicities[7,8].

Symptoms include optic neuritis (damage to optic nerve that may cause pain and temporary vision loss in one eye), acute myelitis (inflammation of spinal cord), area prostrema syndrome (uncontrollable hiccups or nausea and vomiting), and narcolepsy (sleep disorder)**[2].**

Without treatment, within five years of the first attack, about half of NMOSD will be blind, and will be wheelchair users, and approximately a third will die[9]. Disabilities accumulate with relapses, it is therefore important to aggressively treat relapses and prevent relapses with maintenance therapies**[10].** Prognosis has improved with the identification of the AQP4 antibody[11,12].

Participants

To be eligible for the study, participants needed to have been diagnosed with NMOSD, or MOG, or have cared for someone who had one of these conditions, have experienced the healthcare system in Australia, be 18 years of age or older, be able to speak English, and be able to give consent to participate in the study.

Personal Experience, Expectations and Knowledge (PEEK): Study position

In this PEEK study, 18 people diagnosed with NMOSD throughout Australia participated in the study that included a qualitative structured interview and quantitative questionnaire. This study in NMOSD is the only mixed methods study reported in an Australian population, and it includes the most patient interviews worldwide. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Section 2 Demographics

Participants

In this PEEK study, a total of 36 participants were recruited into the study, 18 participants with NMOSD (50.00%), eight participants (22.22%) with MOG and 10 family members or carers to people with NMOSD or MOG (27.78%).

Participants with NMOSD

There were 18 people with NMOSD who took part in this study, the majority were females (n=16, 88.89%). Participants were most commonly aged between 45 to 64 years (n=10, 55.56%).

Participants with NMOSD were most commonly from New South Wales (n=7, 38.89%), Queensland (n=6, 33.33%), or Victoria (n=3, 16.67%). Most participants lived in major cities (n= 15, 83.33%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 12 participants (66.67%) from an area with a high SEIFA score of 7 to 10 (more advantage), and six participants (33.33%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

Less than half of the participants with NMOSD had completed at least some university (n=8, 44.44%). There were seven participants (38.89%) who were employed either full time (n=5, 27.78%), or part time (n=2, 11.11%). There were six participants (33.33%) who were disabled and unable to work, and three participants (16.67%) who were retired. Almost a third of the participants were carers to family members or spouses (n=5, 27.78%).

Other health conditions

Participants with NMOSD reported between zero and 12 other conditions that they had to managed, with a median of 4.00 other conditions (IQR = 2.00) (Table 2.3, Figure 2.2).

The most commonly reported health condition by participants with NMOSD was chronic pain, (n=14, 77.78%), this was followed by sleep problems (n=11, 61.11%) and depression, either self-diagnosed or diagnosed by a doctor (n=9, 50.00%) (Table 2.4, Figure 2.3).

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were moderately limited.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health interfered quite a lot with work or other activities.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems interfered quite a lot with work or other activities.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants had poor energy and a lot of fatigue.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average**,** participants felt happy and calm some of the time, and anxious and depressed some of the time.

The **SF36 Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were moderately limited.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had moderate pain.

The **SF36 General health** scale measures perception of health. On average, participants reported poor health.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants have health that is somewhat worse now compared to one year ago.

Section 3: Symptoms and diagnosis

Experience of symptoms before diagnosis

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

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

Symptoms leading to diagnosis

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

Symptoms leading to diagnosis: Seeking medical attention

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

Symptoms leading to diagnosis: Diagnostic pathway

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

Symptoms leading to diagnosis: Symptom recall

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

Diagnostic tests

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

Time from diagnostic test to diagnosis

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

Time from symptoms to diagnosis

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

Diagnosis provider and location

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

Form of condition

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

Age at diagnosis

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

Number of relapses

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

Year of diagnosis

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

Understanding of disease at diagnosis

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

Emotional support at diagnosis

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

Information at diagnosis

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

Costs at diagnosis

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

Genetic tests and biomarkers

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

Experience of genetic tests and biomarkers

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

Specific biomarkers or genetic markers

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

Understanding of prognosis

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

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common was participants being presented with multiple treatment options and this was described by 11 participants (61.11%). This was followed by participants being presented with one treatment option (n=6, 33.33%).

Conversations about treatment: Participation in discussions

Of the participants who were presented with multiple options six (33.33%) described being told what to do without discussion, and four (22.22%) participated in the decision-making process.

Conversations about treatment: Specific treatments discussed

Some participants described specific treatments that were discussed, the most common was rituximab (n=11, 61.11%), followed by steroids (n=7, 38.89%), and plasma exchange (n=5, 27.78%).

Considerations when making decisions about treatment

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported consideration was side effects as part of multiple aspects that they consider when making decisions about treatment, and this was described by five participants (27.78%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 16 participants (88.89%) that felt the way they made decisions about treatment had changed over time.

Decision-making over time

Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed and/or assertive (n=6, 33.33%).

Personal goals of treatment or care

Participants were asked what their personal goals of treatment or care were. The most common response was participants wanting to maintain their condition/prevent worsening and relapse of their condition (n=7, 38.89%).

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 cancer 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 bought 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 whether they has access to telehealth or remote access. There were nine participants (50.00%) who described not having access to telehealth or remote access and eight participants (44.44%) described having access to telehealth or remote access.

Access to telehealth or remote access: Experience

There were nine participants (50.00%) who did not receive care through telehealth or remote access and so gave no opinion. This was followed by five participants (27.78%) 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.

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common type of information accessed by 15 participants (83.33%) was through the internet, and this was followed by Facebook (n=8, 44.44%) and information from the Guthy-Jackson Foundation (n=6, 33.33%).

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by seven participants (38.89%) was other peoples experiences.

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common response was that no information was not helpful (n=6, 33.33%)

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Overall, the most common theme was online information (n=5, 27.78%).

Information preferences: Rationale

The most common theme reason for their information preference was due to being able to digest information at their own pace (n=7, 38.89%).

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common times that participants described being receptive to receiving information was from the beginning (diagnosis) (n=7, 38.89%), and participants describing being receptive to information after a specific amount of time had passed (n=7, 38.89%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall negative experience (n=11, 61.11%) followed by five participants (27.78%) who described an overall positive experience.

Healthcare professional communication: Reasons for experience

There were eight participants (44.44%) that described health professional communication as limited in relation to their understanding of the condition. Where participants described a positive experience, this related to communication being holistic (two way, supportive and comprehensive conversations) (n=5, 27.78%).

Partners in health

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a moderate ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had excellent recognition and management of symptoms.

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals. Participants with NMOSD were most commonly given information about treatment options (n=10, 55.56%), and disease management (n=6, 33.33%). There were five participants (27.78%) that received very little information from healthcare professionals.

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. Participants with NMOSD most commonly searched for information about disease management (n=16, 88.89%), disease cause (n=15, 83.33%), treatment options (n=12, 66.67%), complementary therapies (n=11, 61.11%), and physical activity (n=10, 55.56%). Half of the participants looked for information about how to interpret test results, dietary information, and psychological/social support (n=9, 50.00%).

Information gaps: participants with NMOSD

The topic most often given to participants by healthcare professionals and not searched for independently was about treatment options (n = 5, 27.78%).

The topics most commonly given to participants by healthcare professionals and searched for independently were disease management (n=5, 27.78%), and treatment options (n=5, 27.78%).

Topics most often not given by health professional and not searched for independently were clinical trials (n=12, 66.67%), hereditary considerations (n=10, 55.56%), and dietary information (n=9, 50.00%).

The most common topics that were searched for and not given by a healthcare professional were disease cause (n=13, 72.22%), disease management (n=11, 61.11%), complementary therapies (n=11, 61.11%), and physical activity (n=10, 55.56%). Half of the participants searched for how to interpret test results, and dietary information without receiving information from healthcare professionals (n=9, 50.00%).

Most accessed information

Participants were asked to rank which information source that they accessed most often. Participants with NMOSD accessed information from non-profits organisations, charities, or patient organisations most often, followed by medical journals, and from the government least often

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. Participants were asked if they had accessed it, and if they had accessed it, how useful it was. There were nine participants with NMOSD (50.00%) that had accessed My Health Record, seven participants (38.89%) that had not. There was one participant (5.56%) that wasn't sure, and one participant (5.56%) that's did not know what it is.

Of those that had accessed My Health Record, there were three participants (33.33%) that thought the usefulness was very poor, two participants (22.22%) that thought it was poor, and four participants (44.44%) found it acceptable)

Section 7: Experience of care and support

Care coordination

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome.

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had poor communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had a moderate navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had moderate communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as moderate.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as good.

Ability to take medicine as prescribed

Participants were asked about their ability to take medicines as prescribed. The majority of participants with NMOSD responded that they took medicine as prescribed all the time (n=11, 61.11%), and seven participants (38.89%) responded that they took medicines as prescribed most of the time. There were no participants that responded that they sometime, never, or rarely took medicines as prescribed.

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. In the general NMOSD population the most common response was that participants and no received any support (n=8, 44.44%). This was followed by receiving support through domestic services (n=7, 38.89%).

Section 8: Quality of life

Experience of quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 16 participants (88.89%) that described a negative impact on quality of life. The most common themes in relation to having a negative impact on quality of life included emotional strain on family/change in relationship dynamics (n=12, 66.67%), and reduced capacity for physical activity (n=6, 33.33%).

Impact on mental health

In the structured interview, participants were asked whether their mental health had been impacted. There were 15 participants (83.33%) who gave a description suggesting that overall, there was at least some impact on mental health.

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotion and mental health. The most common response from six participants (33.33%) was the importance of physical exercise and this was followed by using mindfulness or meditation (n=5, 27.78%).

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health. The most common way that participants reported managing their health was by being physically active (n=7, 38.89%). There were six participants (33.33%) that described the importance of understanding their limitations and five (27.78%) that described the importance of self care e.g. more rest, support for housework etc.

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 12 participants (66.67%) that described a negative impact on relationships. Where participants described relationships being suffering, this was primarily in relation to their reduced capacity for socialising (n=6, 33.33%).

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Overall, there were 10 participants (55.56%) that felt there was an additional burden. Where participants felt there was an additional burden, this was primarily in relation to extra household duties and responsibilities that their family must take on (n=5, 27.78%), and needing extra assistance to get to appointments (n=5, 27.78%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 14 participants (77.78%) that gave a description suggesting that overall there was at least some cost burden. There were 10 participants (55.56%) that spoke about cost burden in relation to needing to take time off work and nine participants (50.00%) that reported cost burden in relation to the cost of treatments (including repeat scripts).

Overall impact of NMOSD on quality of life

In the online questionnaire, participants were asked to rate the overall impact of having a NMOSD or MOG on quality of life. Quality of life was rated on a Likert scale from one to seven, where one is Life was very distressing and seven is Life was great. The median impact of quality of life from NMOSD was 2.00 (IQR= 1.28), in the "life was distressing" range

Experience of anxiety related to disease progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their condition.

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their condition. Overall, the average fear of progression score for NMOSD participants in this study indicated high levels of anxiety.

The responses to individual questions of the Fear of Progression questionnaire for participants with NMOSD showed that 50% or more participants that were often or very often worried about;disease progression (n=11, 61.11%), reaching professional or personal goals (n=12, 66.67%), relatives being diagnosed with disease (n=9, 50.00%), being able to pursue hobbies (n=15, 83.33%), treatment will damage body (n=11, 61.11%), worried about family if anything happens to them (n=11, 61.11%), and not being able to work (n=9, 50.00%).

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common theme was that future treatments will have fewer or less intense side effects (n=6, 33.33%), and this was followed by the expectation that there will be more treatments available/options to treat their condition (e.g. treatments from overseas, those used to treat other conditions) (n=5, 27.78%).

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common theme was the expectation that future information will be more specific to their condition/disease (n=5, 27.78%).

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common theme was the expectation that future communication will be more transparent and information more forthcoming (n=7, 38.89%).

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online) (n=5, 27.78%).

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was low cost/free medical care (n=6, 33.33%). This was followed by being grateful for hospitals (n=6, 33.33%).

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported by participants with NMOSD were: weakness or paralysis of arms and legs, loss of clear vision, and loss of bowel or bladder control.

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care,. The most important aspects to participants with NMOSD were “How safe the medication is and weighing up the risks and benefits”, and “The severity of the side effects”. The least important was “My ability to follow and stick to a treatment regime”.

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The two most important values for participants with NMOSD were: quality of life for patients; and access for all patients to all treatments and services; the least important was economic value to government.

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure. The majority of participants with NMOSD (n=11, 64.11%) would use a treatment for more than 10 years for a good quality of life even if it didn't offer a cure. There were two participants (11.11%) that would take medication for five to 10 years, four participants (22.22%) that would take it for one to four years.

Most effective form of medicine

Participants were asked in the online questionnaire, In what form did they think medicine was most effective in. Participants with NMOSD most commonly responded that they were not sure (n=7, 38.89%), followed by IV form (n=6, 33.33%), and four participants (n=4, 22.22%) thought IV and pill forms were equally effective.

Messages to decision-makers

Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common message was to invest in new treatments and make them more accessible (n=7, 38.89%).

Wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier in relation to their condition. The two main responses were wishing they had known what to expect from their condition (e.g. symptoms, side effects of medication) (n=6, 33.33%) and wishing they had known known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration (n=6,33.33%).

Would this have influenced your decisions

Participants were asked the follow-up question "would this have influenced your decisions," the most common response was that yes this would have influenced their decisions (n=8, 44.44%).

Aspect of treatment or care they would change

In the structured interview, participants were asked if there was anything about their treatment or care they would change. The most common response from six participants (33.33%) was that they would not change any aspect of their care or treatment as they were satisfied with care and treatment received.

Section 1

Introduction and methods

Section 1 Introduction and methodology

About this condition

Neuromyelitis optica spectrum disorder (NMOSD) is an autoimmune disease of the brain and spinal cord, characterised by optic neuritis (inflammation of the optic nerve) and myelitis (inflammation of the spinal cord)[1,2].

Although NMOSD can affect men and women of all ages and ethnicities, middle-aged and elderly women are most commonly affected[5]. The average age of onset is 40 years of age[6], and NMOSD is more common in non-white ethnicities[7,8].

Symptoms include optic neuritis (damage to optic nerve that may cause pain and temporary vision loss in one eye), acute myelitis (inflammation of spinal cord), area prostrema syndrome (uncontrollable hiccups or nausea and vomiting), and narcolepsy (sleep disorder)**[2].**

Without treatment, within five years of the first attack, about half of NMOSD will be blind, and will be wheelchair users, and approximately a third will die[9]. Disabilities accumulate with relapses, it is therefore important to aggressively treat relapses and prevent relapses with maintenance therapies**[10].** Prognosis has improved with the identification of the AQP4 antibody[11,12].

Participants

To be eligible for the study, participants needed to have been diagnosed with NMOSD, or MOG, or have cared for someone who had one of these conditions, have experienced the healthcare system in Australia, be 18 years of age or older, be able to speak English, and be able to give consent to participate in the study.

Personal Experience, Expectations and Knowledge (PEEK): Study position

In this PEEK study, 18 people diagnosed with NMOSD throughout Australia participated in the study that included a qualitative structured interview and quantitative questionnaire. This study in NMOSD is the only mixed methods study reported in an Australian population, and it includes the most patient interviews worldwide. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Introduction

Neuromyelitis optica spectrum disorder (NMOSD) is an autoimmune disease of the brain and spinal cord, characterised by optic neuritis (inflammation of the optic nerve) and myelitis (inflammation of the spinal cord)[1,2].

Incidence, prevalence and mortality statistics

NMOSD is a rare disorder previously thought to be a type of Multiple sclerosis. NMOSD was difficult to distinguish from MS until the discovery of aquaporin 4 (AQP4 antibodies)[3]. The estimated incidence of NMOSD in Australia and NZ is 0.37 per million per year, and estimated prevalence is 0.7 per 100,000[4].

Risks and Symptoms

Although NMOSD can affect men and women of all ages and ethnicities, middle-aged and elderly women are most commonly affected[5]. The average age of onset is 40 years of age[6], and NMOSD is more common in non-white ethnicities[7,8].

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Complications

Without treatment, within five years of the first attack, about half of NMOSD will be blind, and will be wheelchair users, and approximately a third will die[9]. Disabilities accumulate with relapses, it is therefore important to aggressively treat relapses and prevent relapses with maintenance therapies[10]. Prognosis has improved with the identification of the AQP4 antibody[11,12].

Personal Experience, Expectations and Knowledge (PEEK)

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

The research protocol used in PEEK studies is independently driven by CCDR. PEEK studies include a quantitative and qualitative component. The quantitative component is based on a series of validated tools. The qualitative component is the result of two years of protocol testing by CCDR to develop a structured interview that solicits patient experience data and provides patients with the opportunity to provide advice on what they would like to see in relation to future treatment, information and care. The structured interview has also been designed so that the outcomes of PEEK studies can inform policy, research, care, information, supportive care services and advocacy efforts.

Methodology

Participants

To be eligible for the study, participants needed to have been diagnosed with NMOSD, or MOG, or have cared for someone who had one of these conditions, have experienced the healthcare system in Australia, be 18 years of age or older, be able to speak English, and be able to give consent to participate in the study. Recruitment commenced in September 2020 to December 2020.

Ethics

Ethics approval for this study was granted (as a low or negligible risk research study) by the Centre for Community-Driven Research Ethics Committee (Reference CS_Q4_03).

Data collection

Data for the online questionnaire was collected using Zoho Survey (Zoho Corporation Pvt. Ltd. Pleasanton, California, USA, www.zoho.com/survey). Participants completed the survey from September 2020 to December 2020.

There were three researchers who conducted telephone interviews and used standardised prompts throughout the interview. The interviews were recorded and transcribed verbatim. Identifying names and locations were not included

in the transcript. All transcripts were checked against the original recording for quality assurance. Interview data was collected from September 2020 to December 2020.

Online questionnaire (quantitative)

The online questionnaire consisted of the 36-Item Short Form Health Survey (SF36) (RAND Health)[13], a modified Cancer Care Coordination Questionnaire for Patients (CCCQ)[14], the Short Fear of Progression Questionnaire (FOP12)[15], and the Partners in Health version 2 (PIH)[16]. In addition, investigator derived questions about demographics, diagnosis, treatment received and future treatment decisions making were included.

Structured Interview (qualitative)

Interviews were conducted via telephone by registered nurses who were trained in qualitative research. The first set of interview questions guided the patient through their whole experience from when symptoms were noticed up to the present day.

Questionnaire analysis

Statistical analysis was conducted using R included in the packages "car", "dplyr" and "ggplot2" (R 3.3.3 GUI 1.69 Mavericks build (7328). The aim of the statistical analysis of the SF36, CCCQ, FOP12, and PIH responses was to identify variations by participant type, relapses, fear of progression, physical function, gender, age, location of residence, education status and socio-economic status. Scales and subscales were calculated according to reported instructions[13-16].

The Location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics[17].

The level of socio-economic status of participants was evaluated by postcode using the Socio-economic Indexes for Areas (SEIFA) accessed from the Australian Bureau of Statistics[18].

For comparisons by disability, participant type, and age, a one-way analysis of variance (ANOVA) analysis was conducted. A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test. Where the assumptions for the one-way ANOVA were not met, a Kruskal-Wallis rank sum test on care was conducted with post-hoc pairwise comparisons using Wilcoxon rank sum test. When the assumption of equal variances were not met, a Welch one-way test was used with post-hoc pairwise t-tests with no assumption of equal variances.

For all other comparisons, a two-sample t-test was used when assumptions for normality and variance were met, or when assumptions were not met, a Wilcoxon rank sum test with continuity correction was used. Questions where participants were asked to rank preferences were analysed using weighted averages. Weights were applied in reverse, the most preferred option was given the largest weight equal to the number of options, the least preferred option was given the lowest weight of 1.

Structured interviews analysis

A content analysis was conducted using conventional analysis to identify major themes from structured interviews. Text from the interviews were read line-by-line by the lead researcher and then imported into NVivo 8 (QSR International)/MaxQDA. Each question within the interview was individually analysed. Initial categories and definitions were identified and registered in NVivo 8 (QSR International)/MaxQDA. The minimum coded unit was a sentence with paragraphs and phrases coded as a unit.

A second researcher verified the codes and definitions, and the text was coded until full agreement was reached using the process of consensual validation. Where a theme occurred less than 5 times it was not included in the study results, unless this result demonstrated a significant gap or unexpected result.

Data analysis and final reporting was completed in January 2021.

Position of this study

A search was conducted in Pubmed (August 18, 2020) to identify NMOSD quality of life or patient experience studies of adults that had been conducted in the past ten years worldwide (Table 1.1). Meta-analysis studies, studies conducted in developing countries, and studies of less than five participants were excluded.

There were 14 studies identified that collected patient self-reported data. There was a single

qualitative study of 15 NMOSD participants [19], where 15 interviews were focused on quality of life. There were 13 quantitative studies of between five and 522 participants with NMOSD. There were seven studies focused on symptoms[20-26], two studies on COVID-19[27,28], two Quality of life studies[29], one focused on co-morbidities [30], and one on Reproductive history[31]. There were no studies that were conducted in an Australian population.

In this PEEK study, 18 people diagnosed with NMOSD throughout Australia participated in the study that included a qualitative structured interview and quantitative questionnaire. This study in NMOSD is therefore the only mixed methods study reported in an Australian population, and it includes the most patient interviews worldwide. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Table 1.1: PEEK position

Author, Year	Disease and Number of participants (Number of NMOSD in mixed studies)	Location	Design	Focus	PEEK section							
					2: Health status, co-morbidities, health-related quality of life	3: Diagnosis experience, information, support and costs	4: Decision making and healthcare professional discussions	5: Treatment, healthcare system use and access, economic implications	6: Information, communication and self-management	7: Care, support and navigating healthcare system	8: Quality of life, mental health, relationships	9 Expectations, preferences and messages
Beekman, 2019[32]	NMOSD,193	North America	Quantitative	Quality of life	X	X		X			X	X
Mealy, 2019[29]	NMOSD, 21	USA	Quantitative	Quality of life	X							
Seok, 2017[20]	NMOSD, 35	Korea	Quantitative	Symptoms	X	X					X	
Bove, 2017[31]	NMOSD, 217	UK	Quantitative	Reproductive history				X				
Salama, 2020[27]	NMOSD, 186	USA	Quantitative	COVID 19			X	X	X		X	
Eaneff, 2017[21]	NMOSD, 522	International	Quantitative	Symptoms	X	X		X				
Mealy, 2020[22]	NMOSD, 22	USA	Quantitative	Symptoms		X		X			X	
Milewska, 2020[23]	Demyelinating diseases, 64(8)	Poland	Quantitative	Symptoms		X						
Kawahara, 2014[24]	MS/NMO, 45(10)	Japan	Quantitative	Symptoms		X						
Vanotti, 2013[25]	NMOSD, 14	Spain	Quantitative	Symptoms							X	
Shin, 2019[30]	MS/NMO, 59(35)	Korea	Quantitative	Co-morbidities	X	X					X	
Ciampi, 2020[28]	MS/NMO, 409(5)	Chile	Quantitative	COVID 19	X			X				
Methley, 2017[19]	NMOSD, 15	UK	Qualitative (interviews)	Quality of life	X	X				X	X	X
Asseyer, 2018[26]	NMOSD, 49	Germany	Quantitative	Symptoms	X	X					X	

Abbreviations and terminology

AQP4	Aquaporin-4
ASGS	The Australian Statistical Geography Standard from the Australian Bureau of Statistics, defines remoteness and urban/rural definitions in Australia
CCDR	Centre for Community-Driven Research
dF	Degrees of Freedom. The number of values in the final calculation of a statistic that are free to vary.
f	The F ratio is the ratio of two mean square values, used in an ANOVA comparison. A large F ratio means that the variation among group means is more than you'd expect to see by chance.
FOP	Fear of Progression. Tool to measure anxiety related to progression
IQR	Interquartile range. A measure of statistical dispersion, being equal to the difference between 75th and 25th percentiles, or between upper and lower quartiles.
MOG	Myelin oligodendrocyte glycoprotein
NMOSD	Neuromyelitis optica spectrum disorders
p	Probability value. A small *p*-value (typically ≤ 0.05) indicates strong. A large *p*-value (> 0.05) indicates weak evidence.
PEEK	Patient Experience, Expectations and Knowledge
PIH	Partners in Health
SD	Standard deviation. A quantity expressing by how much the members of a group digger from the mean value for the group/
SEIFA	Socio-Economic Indexes for Areas (SEIFA) ranks areas in Australia according to relative socio-economic advantage and disadvantage. This is developed by the Australian Bureau of Statistics.
SF36	Short Form Health Survey 36
t	t-Statistic. Size of the difference relative to the variation in your sample data.
Tukey HSD	Tukey's honestly significant difference test. It is used in this study to find 5significantly different means following an ANOVA test.
W	The W statistic is the test value from the Wilcoxon Rank sum test. The theoretical range of W is between 0 and (number in group one) x (number in group 2). When W=0, the two groups are exactly the same.
X^2	Chi-squared. Kruskal-Wallis test statistic approximates a chi-square distribution. The Chi-square test is intended to test how likely it is that an observed distribution is due to chance.

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Section 2

Demographics

Section 2 Demographics

Participants

In this PEEK study, a total of 36 participants were recruited into the study, 18 participants with NMOSD (50.00%), eight participants (22.22%) with MOG and 10 family members or carers to people with NMOSD or MOG (27.78%).

Participants with NMOSD

There were 18 people with NMOSD who took part in this study, the majority were females (n=16, 88.89%). Participants were most commonly aged between 45 to 64 years (n=10, 55.56%).

Participants with NMOSD were most commonly from New South Wales (n=7, 38.89%), Queensland (n=6, 33.33%), or Victoria (n=3, 16.67%). Most participants lived in major cities (n= 15, 83.33%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 12 participants (66.67%) from an area with a high SEIFA score of 7 to 10 (more advantage), and six participants (33.33%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

Less than half of the participants with NMOSD had completed at least some university (n=8, 44.44%). There were seven participants (38.89%) who were employed either full time (n=5, 27.78%), or part time (n=2, 11.11%). There were six participants (33.33%) who were disabled and unable to work, and three participants (16.67%) who were retired. Almost a third of the participants were carers to family members or spouses (n=5, 27.78%).

Other health conditions

Participants with NMOSD reported between zero and 12 other conditions that they had to managed, with a median of 4.00 other conditions (IQR = 2.00) (Table 2.3, Figure 2.2).

The most commonly reported health condition by participants with NMOSD was chronic pain, (n=14, 77.78%), this was followed by sleep problems (n=11, 61.11%) and depression, either self-diagnosed or diagnosed by a doctor (n=9, 50.00%) (Table 2.4, Figure 2.3).

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were moderately limited.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health interfered quite a lot with work or other activities.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems interfered quite a lot with work or other activities.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants had poor energy and a lot of fatigue.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average**,** participants felt happy and calm some of the time, and anxious and depressed some of the time.

The **SF36 Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were moderately limited.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had moderate pain.

The **SF36 General health** scale measures perception of health. On average, participants reported poor health.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants have health that is somewhat worse now compared to one year ago.

Participants

In this PEEK study, a total of 36 participants were recruited into the study, 18 participants with NMOSD (50.00%), eight participants (22.22%) with MOG and 10 family members or carers to people with NMOSD or MOG (27.78%) (Table 2.1, Figure 2.1).

Table 2.1: Participants

Participants	Number (n=36)	Percent
NMOSD	18	50.00
MOG	8	22.22
Family and carers	10	27.78

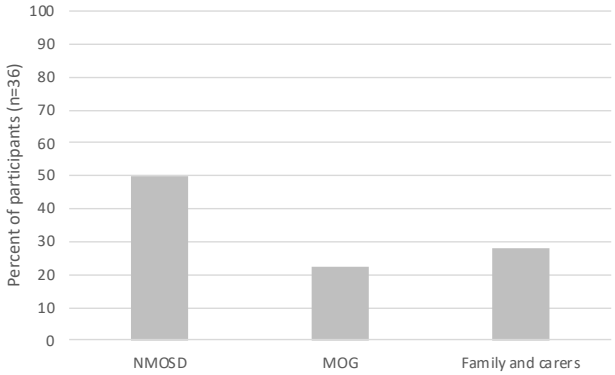

Figure 2.1: Participants

Demographics

Participants with NMOSD

There were 18 people with NMOSD who took part in this study, the majority were females (n=16, 88.89%). Participants were most commonly aged between 45 to 64 years (n=10, 55.56%).

Participants were most commonly from New South Wales (n=7, 38.89%), Queensland (n=6, 33.33%), or Victoria (n=3, 16.67%). Most participants lived in major cities (n= 15, 83.33%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 12 participants (66.67%) from an area with a high SEIFA score of 7 to 10 (more advantage), and six participants (33.33%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

Less than half of the participants had completed at least some university (n=8, 44.44%). There were seven participants (38.89%) who were employed either full time (n=5, 27.78%), or part time (n=2, 11.11%). There were six participants (33.33%) who were disabled and unable to work, and three participants (16.67%) who were retired.

Almost a third of the participants were carers to family members or spouses (n=5, 27.78%). The demographics of participants with NMOSD are listed in Table 2.2.

Participants with MOG

There were eight people with MOG who took part in this study, the majority were females (n=5, 62.50%).

Half of the participants were aged between 45 to 54 years (n=4, 50.00%).

Participants were most commonly from New South Wales (n=3, 37.50%), or Victoria (n=2, 25.00%). Most participants lived in major cities (n= 6, 75.00%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with five participants (62.50%) from an area with a high SEIFA score of 7 to 10 (more advantage), and three participants (37.50%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

Most of the participants had completed at least some university (n=5, 62.50%). Half of the participants with MOG were employed either full or part time (n=4, 50.00%).

Half of the participants were carers to family members or spouses (n=4, 50.00%). The demographics of participants with MOG are listed in Table 2.2.

Family and carers

There were 10 family members or carers of people with NMOSD or MOG who took part in this study, the majority were female (n=8, 80.00%), and were most commonly aged 55 to 64 (n=6, 60.00%).

The majority of carers lived in major cities (n=8, 80.00%), and most commonly lived in NSW (n=3, 30.00%). The demographics of carers are listed in Table 2.2.

Table 2.2: Demographics

Demographics	Definition	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG		Family and carers	
		Number (n=18)	Percent	Number (n=8)		Number (n=26)	Percent	Number (n=10)	Percent
Gender	Female	16	88.89	5	62.50	21.00	80.77	8	80.00
	Male	2	11.11	3	37.50	5.00	19.44	2	20.00
Age	18 to 34	3	16.67	0	0.00	3.00	8.33	0	0.00
	35 to 44	4	22.22	2	25.00	6.00	16.67	2	20.00
	45 to 54	5	27.78	4	50.00	9.00	25.00	2	20.00
	55 to 64	5	27.78	1	12.50	6.00	16.67	6	60.00
	65 to 74	1	5.56	1	12.50	2.00	5.56	0	0.00
	75 or older	0	0.00	0	0.00	0.00	0.00	0	0.00
Location	Major cities	15	83.33	6	75.00	21.00	80.56	8	80.00
	Inner regional	1	5.56	2	25.00	3.00	13.89	2	20.00
	Outer regional	2	11.11	0	0.00	2.00	5.56	0	0.00
State	Australian Capital Territory	1	5.56	1	12.50	2.00	11.11	2	20.00
	New South Wales	7	38.89	3	37.50	10.00	36.11	3	30.00
	Queensland	6	33.33	0	0.00	6.00	19.44	1	10.00
	South Australia	0	0.00	1	12.50	1.00	2.78	0	0.00
	Victoria	3	16.67	2	25.00	5.00	19.44	2	20.00
	Western Australia	1	5.56	1	12.50	2.00	11.11	2	20.00
Socio-Economic Indexes for Areas (SEIFA)	1 to 2	2	11.11	3	37.50	5.00	16.67	1	6.00
	3 to 4	0	0.00	1	12.50	1.00	5.56	1	2.00
	5 to 6	4	22.22	1	12.50	5.00	22.22	3	8.00
	7 to 8	4	22.22	2	25.00	6.00	22.22	2	8.00
	9 to 10	8	44.44	1	12.50	9.00	33.33	3	12.00
Race/ethnicity	Caucasian/white	14	77.78	7	87.50	21.00	80.56	8	80.00
	Other	4	22.22	1	12.50	5.00	19.44	2	20.00
Education	Less than high school degree	3	16.67	1	12.50	4.00	16.67	2	20.00
	High school degree or equivalent	3	16.67	2	25.00	5.00	13.89	0	0.00
	Some college but no degree	1	5.56	0	0.00	1.00	8.33	2	20.00
	Trade	3	16.67	0	0.00	3.00	8.33	0	0.00
	Associate degree	0	0.00	0	0.00	0.00	2.78	1	10.00
	Bachelor degree	7	38.89	3	37.50	10.00	30.56	1	10.00
	Graduate degree	1	5.56	2	25.00	3.00	19.44	4	40.00
Employment	Employed, working full time	5	27.78	3	37.50	8.00	36.11	5	50.00
	Employed, working part time	2	11.11	1	12.50	3.00	13.89	2	20.00
	Full/part time study	1	5.56	0	0.00	1.00	5.56	1	10.00
	Full/part time carer	1	5.56	0	0.00	1.00	5.56	1	10.00
	Not employed, looking for work	0	0.00	1	12.50	1.00	2.78	0	0.00
	Receiving Centrelink support	2	11.11	1	12.50	3.00	11.11	1	10.00
	Disabled, not able to work	6	33.33	1	12.50	7.00	19.44	0	0.00
	Retired	3	16.67	1	12.50	4.00	11.11	0	0.00
Carer status	I am not a carer	13	72.22	4	50.00	0.00	0.00	17	47.22
	Children	4	22.22	4	50.00	4.00	40.00	12	33.33
	Parents	1	5.56	0	0.00	0.00	0.00	1	2.78
	Spouse	1	5.56	0	0.00	6.00	60.00	7	19.44

Other health conditions

Participants were asked about health conditions, other than NMOSD or MOG, that they had to manage. Participants could choose from a list of common health conditions and could specify other conditions (Table 2.4, Figure 2.3).

Participants with NMOSD

Participants with NMOSD reported between zero and 12 other conditions that they had to managed, with a median of 4.00 other conditions (IQR = 2.00) (Table 2.3, Figure 2.2).

The most commonly reported health condition was chronic pain, (n=14, 77.78%), this was followed by sleep problems (n=11, 61.11%) and depression, either self-diagnosed or diagnosed by a doctor (n=9, 50.00%) (Table 2.4, Figure 2.3).

Participants with MOG

Participants with MOG reported between one and eight other conditions that they had to managed, with a median of 4.00 other conditions (IQR = 3.50) (Table 2.3, Figure 2.2).

The most commonly reported health conditions were sleep problems (n=6, 75.00%), this was followed by chronic pain (n=5, 62.50%) (Table 2.4, Figure 2.3).

Family and carers

Family and cares reported between zero and four health conditions (median = 2.00, IQR = 2.75). The most commonly diagnosed condition was anxiety (n=3, 30.00%) (Table 2.3, Figure 2.2).

Table 2.3: Number of other health conditions

Number of other health conditions	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG		Family and carers	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent	Number (n=10)	Percent
No other conditions	1	5.56	0	0.00	1	3.85	3	30.00
1	1	5.56	2	25.00	3	11.54	1	10.00
2	1	5.56	0	0.00	1	3.85	2	20.00
3	3	16.67	2	25.00	5	19.23	3	30.00
4	6	33.33	0	0.00	6	23.08	1	10.00
5	3	16.67	1	12.50	4	15.38	0	0.00
6 or more	3	16.67	3	37.50	6	23.08	0	0.00

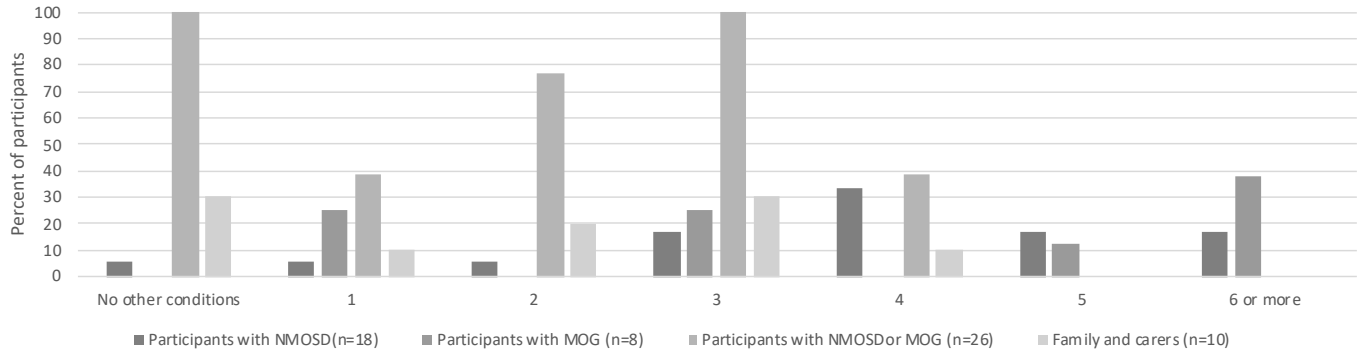

Figure 2.2: Number of other health conditions

Table 2.4: Other health conditions

Other health conditions	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG		Family and carers	
	Number (n=18)	Percent	Number (n=8)		Number (n=26)	Percent	Number (n=10)	Percent
Chronic pain	14	77.78	5	62.50	19	73.08	0	0.00
Sleep problems or insomnia	11	61.11	6	75.00	17	65.38	2	20.00
Depression (Self or doctor diagnosed)	9	50.00	2	25.00	11	42.31	1	10.00
-Depression (Self diagnosed)	4	22.22	0	0.00	4	15.38	1	10.00
-Depression (Diagnosed by a doctor)	5	27.78	0	0.00	5	19.23	1	10.00
Anxiety (Self or doctor diagnosed)	7	38.89	3	37.50	10	38.46	3	30.00
-Anxiety (self diagnosed)	2	11.11	0	0.00	2	7.69	3	30.00
-Anxiety (diagnosed by a doctor)	5	27.78	0	0.00	5	19.23	0	0.00
Arthritis	7	38.89	2	25.00	9	34.62	1	10.00
High cholesterol	4	22.22	2	25.00	6	23.08	2	20.00
Atrial fibrillation or arrhythmias	1	5.56	2	25.00	3	11.54	1	10.00
Asthma	0	0.00	2	25.00	2	7.69	1	10.00
Diabetes	2	11.11	0	0.00	2	7.69	1	10.00
Stroke	2	11.11	0	0.00	2	7.69	0	0.00
Cancer	0	0.00	2	25.00	2	7.69	1	10.00
Hypertension	1	5.56	0	0.00	1	3.85	2	20.00
Chronic heart failure	1	5.56	0	0.00	1	3.85	0	0.00
Angina	1	5.56	0	0.00	1	3.85	0	0.00
COPD	0	0.00	1	12.50	1	3.85	0	0.00
Chronic kidney disease	0	0.00	0	0.00	0	0.00	0	0.00
Participants with other specified health conditions	7	38.89	4	50.00	11	42.31	3	30.00

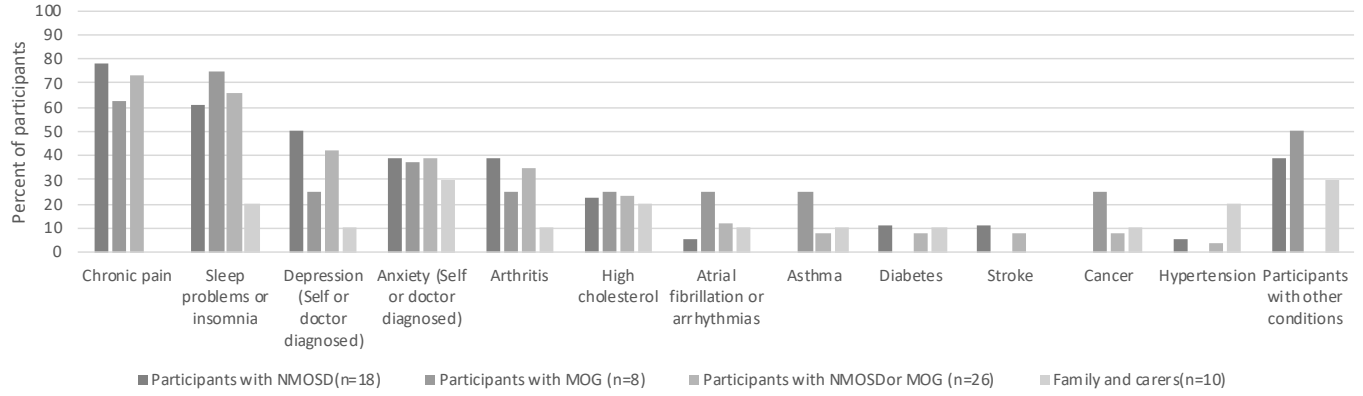

Figure 2.3: Other health conditions

Subgroup analysis

Subgroup analysis are included throughout the study and the subgroups are listed in Table 2.5.

Participant type were grouped according to diagnosis of NMOSD, MOG, and family and carers; the *NMOSD* group includes participants who had a NMOSD diagnosis, (n=18, 50.00%), participants who had a MOG diagnosis were included in the *MOG* group (n=8, 22.22%), participants in the *NMOSD or*

MOG groups were included in the *NMOSD and MOG* subgroup (n=26, 72.22), and family members or carers of people with NMOSD or MOG were included in the *Family and carers* subgroup (n=10, 27.78%).

Comparisons were made by NMOSD **relapses**, those less than two relapses were included in the *fewer relapses* subgroup (n=9, 50.00%), and those that had three or more relapses, in the *more relapses* subgroup (n=9, 50.00%). Only participants with NMOSD were included in this comparison.

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Participants that scored over 41 in the **fear of progression** questionnaire were included in the *High to very high fear* subgroup (n=10, 55.56%), and those that scored less than 41 were included in the *Low to moderate fear* subgroup (n=8, 44.44%). Only participants with NMOSD were included in this comparison.

The SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. Comparisons were made by **physical function**, participants that scored in the lowest three quintiles of the SF36 Physical functioning scale were included in the *Moderate to very poor physical function* subgroup (n=9, 50.00%), and participants that scored in the highest two quintiles were included in the *Good to very good physical function* subgroup (n=9, 50.00%). Only participants with NMOSD were included in this comparison.

Comparisons were made by **Education** status, between those with trade or high school qualifications, *trade or high school* (n=10, 55.56%), and those with a university qualification, *University* (n= 8, 44.44%). Only participants with NMOSD were included in this comparison.

Comparisons were made by **socioeconomic status**, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1 to 6, *Mid to low status* (n=6, 33.33%) compared to those with a higher SEIFA score of 7 to 10, *Higher status* (n=12, 66.67%) . Only participants with NMOSD were included in this comparison.

Participants were grouped according to **age,** with comparisons made between participants *Aged 18 to 44* (n=7, 38.89%), , and *Aged 45 or older* (n=11, 61.11%). Only participants with NMOSD were included in this comparison.

There were 16 females (n=16, 88.89%) with NMOSD, however, there were too few males (n=2, 11.11%) for comparisons to be made. Data by **gender** is displayed for NMOSD participants throughout the study, but no analysis conducted.

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. There were 15 participants with NMOSD (83.33%) that lived in *Metropolitan* areas, however, too few participants with NMOSD lived in *Regional or remote* areas (16.67%) for comparisons to be made. Data by **location** is displayed for NMOSD participants throughout the study, but no analysis conducted.

Table 2.5: Subgroups

Subgroup	Characteristic	Number (n=18)	Percent
Participant type (n=36)	*NMOSD*	18	50.00
	MOG	8	22.22
	NMOSD and MOG	26	72.22
	Family and carers	10	27.78
Relapses	*Fewer relapses*	9	50.00
	More relapses	9	50.00
Fear of progression	*Low to moderate fear*	8	44.44
	High to very high fear	10	55.56
Physical function	*Moderate to very poor physical function*	9	50.00
	Good to very good physical function	9	50.00
Education	*Trade or high school*	10	55.56
	University	8	44.44
Socioeconomic advantage	*Mid to low status*	6	33.33
	Higher status	12	66.67
Age	*Aged 18 to 44*	7	38.89
	Aged 45 or older	11	61.11
Gender	*Female*	16	88.89
	Male	2	11.11
Location	*Regional or remote*	3	16.67
	Metropolitan	15	83.33

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 2.6, for scales that had a normal distribution, the mean and SD should be used as an average measure.

The overall scores for the cohort were in the middle of the scale for **SF36 Physical functioning** (mean = 53.61, SD = 31.98), **SF36 Emotional well-being** (mean = 57.56, SD = 24.85), **SF36 Social functioning** (mean = 47.92, SD = 22.79), and **SF36 Pain** (mean = 43.06, SD = 30.07). This indicates moderate physical function, emotional well-being, social functioning, and pain.

he overall scores for the cohort were in the second lowest quintile for **SF36 Energy/Fatigue** (mean = 28.33, SD = 20.72), **SF36 General health** (mean = 32.78, SD = 23.65), and **SF36 Health change** (median = 37.5, IQR = 43.75) indicating poor energy/fatigue, general health and worse health than a year ago.

The overall scores for the cohort were in the lowest quintile for **SF36 Role functioning/physical** (median = 0, IQR = 87.5), and **SF36 Role functioning/emotional** (median = 0, IQR = 66.67) indicating that physical and emotional health interfered quite a bit with work or other activities.

Comparisons of SF36 have been made based on **participant type** (Tables 2.7 to 2.12, Figures 2.4 to 2.12), **relapses** (Tables 2.13 to 2.14, Figures 2.13 to 2.21), **fear of progression** (Tables 2.15 to 2.16, Figures 2.22 to 2.30), **physical function** (Tables 2.17 to 2.18, Figures 2.31 to 2.38), **education,** (Tables 2.19 to 2.20, Figures 2.39 to 2.47), **socioeconomic status** (Table 2.21 to 2.22, Figures 2.48 to 2.56), **age** (Tables 2.23 to 2.24, Figures 2.57 to 2.65), **gender** (Table 2.25), and **location** (Tables 2.26).

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were moderately limited.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health interfered quite a lot with work or other activities.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems interfered quite a lot with work or other activities.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants had poor energy and a lot of fatigue.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average**,** participants felt happy and calm some of the time, and anxious and depressed some of the time.

The **SF36 Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were moderately limited.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had moderate pain.

The **SF36 General health** scale measures perception of health. On average, participants reported poor health.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants have health that is somewhat worse now compared to one year ago.

Table 2.6: SF36 summary statistics

SF36 scale (n=18)	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning*	53.61	31.98	62.50	53.75	0 to 100	3
Role functioning/physical	30.56	45.82	0.00	87.50	0 to 100	1
Role functioning/emotional	31.48	43.49	0.00	66.67	0 to 100	1
Energy/Fatigue*	28.33	20.72	27.50	25.00	0 to 100	2
Emotional well-being*	57.56	24.85	62.00	34.00	0 to 100	3
Social functioning*	47.92	22.79	50.00	37.50	0 to 100	3
Pain*	43.06	30.07	45.00	42.50	0 to 100	3
General health*	32.78	23.65	32.50	32.50	0 to 100	2
Health change	43.06	35.15	37.50	43.75	0 to 100	2

*Normal distribution, use mean and SD as average measure

Comparisons of SF36 scales by participant type

Participant type were grouped according to diagnosis of NMOSD, MOG, and family and carers; the *NMOSD* group includes participants who had a NMOSD diagnosis, (n=18, 50.00%), participants who had a MOG diagnosis were included in the *MOG* group (n=8, 22.22%), participants in the *NMOSD or MOG* groups were included in the *NMOSD and MOG* subgroup (n=26, 72.22), and family members or carers of people with NMOSD or MOG were included in the *Family and carers* subgroup (n=10, 27.78%).

Boxplots of each SF36 scale by **participant type** are displayed in Figures 2.4 to 2.12, summary statistics are displayed in Tables 2.7, 2.9, and 2.11.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 2.7). A Tukey HSD test was used post hoc to identify the source of any differences identified in the one-way ANOVA test (Table 2.8).

When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 2.9). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test (Table 2.10).

When the assumption of equal variances were not met, a Welch one-way test was used with post hoc pairwise t-tests with no assumption of equal variances (Tables 2.11 to 2.12).

A one way ANOVA test indicated a statistically significant difference in the **SF36 Energy/fatigue** scale between groups, F(3,58)=6.23, p=0.0010 (Table 2.7). Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants in the *Family and carers* subgroup (mean=56.00, SD=23.78) was significantly higher compared to participants in the *NMOSD* (mean=28.33, SD=20.72, p=0.0047), *MOG* (mean = 22.50, SD=15.35, p=0.0044), and *NMOSD and MOG* (mean=26.54, SD=19.12, p=0.0012) subgroups (Table 2.8).

A one way ANOVA test indicated a statistically significant difference in the **SF36 Social functioning** scale between groups, F(3,58)=4.67, p=0.0055) (Table 2.7). Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants in the *Family and carers* subgroup (mean=78.75, SD=23.61) was significantly higher compared to participants in the *NMOSD* (mean=47.92, SD=22.79, p=0.0048), and *NMOSD and MOG* (mean=51.92, SD=22.27, p=0.0107) subgroups (Table 2.8).

A Kruskal-Wallis test indicated a statistically significant difference in the **SF36 Physical functioning** scale between groups, $\chi^2(3)=14.80$, p=0.0020 (Table 2.9). Wilcoxon rank sum tests between groups indicated that participants in the *Family and carers* subgroup (median=92.50, IQR=12.50) was significantly higher compared to participants in the *NMOSD* (median=62.50, IQR=53.75, p=0.0045), *MOG* (median=35.00, IQR=56.25, p=0.0073), and *NMOSD and MOG* (median=57.50, IQR=57.50, p=0.0027) subgroups (Table 2.10).

A Kruskal-Wallis test indicated a statistically significant difference in the **SF36 Role functioning/physical** scale between groups, $\chi^2(3)=13.70$, p=0.0033 (Table 2.9). Wilcoxon rank sum tests between groups indicated that participants in the *Family and carers* subgroup (median=100.00,IQR =0.00) was significantly higher compared to participants in the *NMOSD (*median=0.00, IQR=87.50, p=0.0098*), MOG (*median=0.00, IQR=12.50, p=0.0098*), and NMOSD and MOG (*median=0.00, IQR=50.00, p=0.0065*)* subgroups (Table 2.10).

A Kruskal-Wallis test indicated a statistically significant difference in the **SF36 Role functioning/emotional** scale between groups,

$\chi^2(3)=10.74$, p=0.0132 (Table 2.9). Wilcoxon rank sum tests between groups indicated that participants in the *Family and carers* subgroup (median=100.00, IQR =25.00) was significantly higher compared to participants in the *NMOSD* (median=0.00, IQR=66.67, p=0.0370) subgroup (Table 2.10).

A Kruskal-Wallis test indicated a statistically significant difference in the **SF36 Emotional well-being** between groups, $\chi^2(3)=9.44$, p=0.0239 (Table 2.9). Wilcoxon rank sum tests between groups indicated that participants in the *Family and carers* subgroup (median=82.00, IQR=14.00) was significantly higher compared to participants in the *NMOSD (median=62.00, IQR=34.00, p=0.0320), and NMOSD and MOG (median=64.00, IQR=30.00, p=0.0320)* subgroups (Table 2.10).

A Kruskal-Wallis test indicated a statistically significant difference in the **SF36 General health** between groups, $\chi^2(3)=14.77$, p=0.0020 (Table 2.9). Wilcoxon rank sum tests between groups indicated that participants in the *Family and carers* subgroup (median=67.50, IQR =22.50) was significantly higher compared to participants in the *NMOSD* (median=32.50, IQR=32.50, p=0.0045*), MOG (*median=25.00, IQR=21.25, p=0.0065*), and NMOSD and MOG (*median=30.00, IQR=25.00, p=0.0026*)* subgroups (Table 2.10).

A Welch one-way test indicated indicated a statistically significant difference in the **SF36 Pain** scale between groups F(3, 26.28)=20.55, p<0.0001 (Table 2.11). Post-hoc pairwise t-tests with no assumption of equal variances indicated that the mean score for participants in the *Family and carers (*mean=86.75, SD=11.43*)* was significantly higher compared to participants in the *NMOSD* (mean=43.06, SD=30.07, p=0.0045*), MOG* (mean=53.13, SD=14.13, p=0073*), and NMOSD and MOG* (mean=46.15, SD=26.33, p=0.0027) subgroups (Table 2.12*).*

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, participants in the *Family and Carer* subgroup scored higher than participants in the *NMOSD; MOG; and NMOSD and MOG* subgroups. This indicates that physical activities were not limited at all for participants in the *Family and Carer* subgroup, compared to slightly limited for participants in the *NMOSD* subgroup, moderately limited for participants in the *NMOSD and MOG* subgroup, and limited quite a bit for participants in the *MOG* subgroup.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, participants in the *Family and Carer* subgroup scored higher than participants in the *NMOSD; MOG; and NMOSD and MOG* subgroups. This indicates that physical health did not at all interfere with work or other activities for participants in subgroup *Family and Carer,* compared to extremely interfered with work or other activities for participants in the *NMOSD, MOG,* and *NMOSD and MOG* subgroups.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, participants in the *Family and Carer* subgroup scored higher than participants in the *NMOSD* subgroup. This indicates that emotional problems did not at all interfere with work or other activities for participants in *Family and Carer* subgroup*,* compared to extremely interfered with work or other activities for participants in the *NMOSD* subgroup.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants in the *Family and Carer* subgroup scored higher than participants in the *NMOSD; MOG; and NMOSD and MOG* subgroups. This indicates that participants in the *Family and Carer* subgroup felt tired some of the time and had energy some of the time, compared participants in the *NMOSD, MOG,* and *NMOSD and MOG* subgroups who felt tired most of the time, had energy a little of the time.

The **SF36 Emotional well-being**, which scale measures how a person feels, for example happy, calm, depressed or anxious**.** On average, participants in the *Family and Carer* subgroup scored higher than participants in the *NMOSD; and NMOSD and MOG* subgroups. This indicates that participants in the *Family and Carer* subgroup felt happy and calm all of the time, compared participants in the *NMOSD,* and *NMOSD and MOG* subgroups who felt happy and calm most of the time, and anxious and depressed a little of the time.

The **SF36 Social functioning** scale measures **l**imitations on social activities due to physical or emotional problems. On average, participants in the *Family and Carer* subgroup scored higher than participants in the *NMOSD; and NMOSD and MOG*

subgroups. This indicates that social activities were slightly limited for participants in the *Family and Carer* subgroup, compared to social activities were moderately limited for participants in *NMOSD; and NMOSD and MOG* subgroups.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants in the *Family and Carer* subgroup scored higher than participants in the *NMOSD; MOG; and NMOSD and MOG* subgroups. This indicates that participants in the subgroup *Family and Carer* did not have any pain, compared to participants in the *NMOSD; MOG; and NMOSD and MOG* subgroups, who had moderate pain.

The **SF36 General health** scale measures perception of health. On average, participants in the *Family and Carer* subgroup scored higher than participants in the *NMOSD; MOG; and NMOSD and MOG* subgroups. This indicates that participants in the *Family and Carer* subgroup reported good health, compared to participants in the *NMOSD; MOG; and NMOSD and MOG* subgroups who reported poor general health.

Table 2.7: SF36 by participant type summary statistics and one-way ANOVA test

SF36 scale	Group	Number (n=36)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Energy/Fatigue	*NMOSD*	18	50.00	28.33	20.72	Between groups	7468.00	3	2489.40	6.23	0.0010*
	MOG	8	22.22	22.50	15.35	Within groups	23178.00	58	399.60		
	NMOSD and MOG	26	72.22	26.54	19.12	Total	30646.00	61			
	Family and carers	10	27.78	56.00	23.78						
Social functioning	*NMOSD*	18	50.00	47.92	22.79	Between groups	6975.00	3	2325.00	4.67	0.0055*
	MOG	8	22.22	60.94	19.41	Within groups	28884.00	58	498.00		
	NMOSD and MOG	26	72.22	51.92	22.27	Total	35859.00	61			
	Family and carers	10	27.78	78.75	23.61						

*Significant at p<0.005

Table 2.8: SF36 by participant type one-way post hoc Tukey HSD test

SF36 scale	Group	Difference	Lower	Upper	P adjusted
Energy/fatigue	*MOG - NMOSD*	-5.83	-28.30	16.64	0.9018
	NMOSD and MOG - NMOSD	-1.79	-18.01	14.42	0.9912
	Family and carers - NMOSD	27.67	6.81	48.52	0.0047*
	NMOSD - MOG	4.04	-17.34	25.42	0.9588
	Family and carers - MOG	33.50	8.42	58.58	0.0044*
	Family and carers - NMOSD and MOG	29.46	9.79	49.14	0.0012*
Social functioning	*MOG - NMOSD*	13.02	-12.06	38.10	0.5211
	NMOSD and MOG - NMOSD	4.01	-14.09	22.11	0.9361
	Family and carers - NMOSD	30.83	7.55	54.11	0.0048*
	NMOSD - MOG	-9.01	-32.88	14.85	0.7505
	Family and carers - MOG	17.81	-10.19	45.81	0.3420
	Family and carers - NMOSD and MOG	26.83	4.86	48.79	0.0107*

*Significant at p<0.005

Table 2.9: SF36 by participant type summary statistics and Kruskal Wallis test

SF36 scale	Group	Number (n=36)	Percent	Median	IQR	C^2	dF	p-value
Physical functioning	*NMOSD*	18	50.00	62.50	53.75	14.80	3	0.0020*
	MOG	8	22.22	35.00	56.25			
	NMOSD and MOG	26	72.22	57.50	57.50			
	Family and carers	10	27.78	92.50	12.50			
Role functioning/physical	*NMOSD*	18	50.00	0.00	87.50	13.70	3	0.0033*
	MOG	8	22.22	0.00	12.50			
	NMOSD and MOG	26	72.22	0.00	50.00			
	Family and carers	10	27.78	100.00	0.00			
Role functioning/emotional	*NMOSD*	18	50.00	0.00	66.67	10.74	3	0.0132*
	MOG	8	22.22	100.00	41.67			
	NMOSD and MOG	26	72.22	33.33	100.00			
	Family and carers	10	27.78	100.00	25.00			
Emotional well-being	*NMOSD*	18	50.00	62.00	34.00	9.44	3	0.0239*
	MOG	8	22.22	70.00	16.00			
	NMOSD and MOG	26	72.22	64.00	30.00			
	Family and carers	10	27.78	82.00	14.00			
General health	*NMOSD*	18	50.00	32.50	32.50	14.77	3	0.0020*
	MOG	8	22.22	25.00	21.25			
	NMOSD and MOG	26	72.22	30.00	25.00			
	Family and carers	10	27.78	67.50	22.50			
Health change	*NMOSD*	18	50.00	37.50	43.75	3.76	3	0.2881
	MOG	8	22.22	25.00	31.25			
	NMOSD and MOG	26	72.22	25.00	25.00			
	Family and carers	10	27.78	50.00	0.00			

*Significant at p<0.005

Table 2.10: SF36 by participant type one-way post hoc Wilcoxon rank sum test p-values

SF36 scale	Group	*NMOSD*	*MOG*	*NMOSD and MOG*
Physical functioning	*MOG*	0.8481	-	-
	NMOSD and MOG	0.8481	0.8481	-
	Family and carers	0.0045*	0.0073*	0.0027*
Role functioning/physical	*MOG*	0.8265	-	-
	NMOSD and MOG	0.8265	0.8265	-
	Family and carers	0.0098*	0.0098*	0.0065*
Role functioning/emotional	*MOG*	0.0600	-	-
	NMOSD and MOG	0.3910	0.1550	-
	Family and carers	0.0370*	0.7100	0.0600
Emotional well-being	*MOG*	0.3610	-	-
	NMOSD and MOG	0.6150	0.4670	-
	Family and carers	0.0320*	0.1180	0.0320*
General health	*MOG*	0.9426	-	-
	NMOSD and MOG	0.9426	0.9426	-
	Family and carers	0.0045*	0.0065*	0.0026*

*Significant at p<0.005

Table 2.11: SF36 by participant type summary statistics and Welch one-way test

SF36 scale	Group	Number (n=36)	Percent	Mean	SD	F	dF1	dF2	P-value
Pain	*NMOSD*	18	50.00	43.06	30.07	20.55	3	26.28	<0.0001*
	MOG	8	22.22	53.13	14.13				
	NMOSD and MOG	26	72.22	46.15	26.33				
	Family and carers	10	27.78	86.75	11.43				

*Significant at p<0.005

Table 2.12: SF36 by participant type one-way post hoc pairwise t-tests p-values

SF36 scale	Group	*NMOSD*	*MOG*	*NMOSD and MOG*
Pain	*MOG*	0.8481	-	-
	NMOSD and MOG	0.8481	0.8481	-
	Family and carers	0.0045*	0.0073*	0.0027*

*Significant at p<0.005

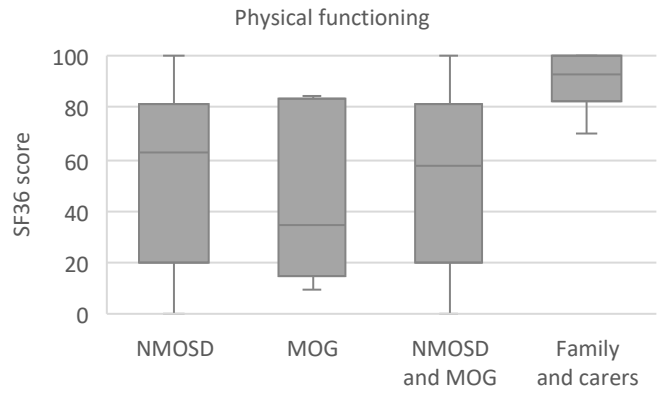

Figure 2.4: Boxplot of SF36 Physical functioning by participant type

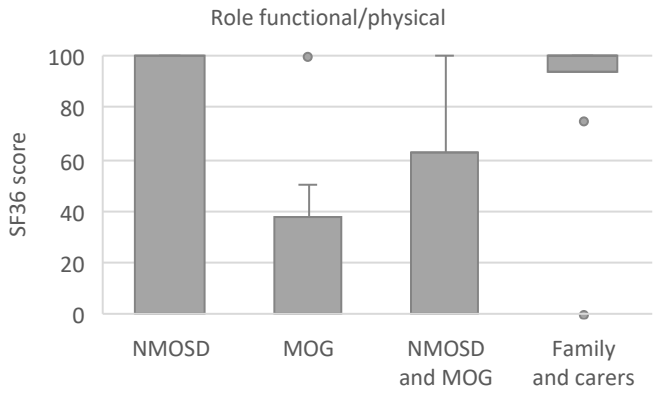

Figure 2.5: Boxplot of SF36 Role functioning/physical by participant type

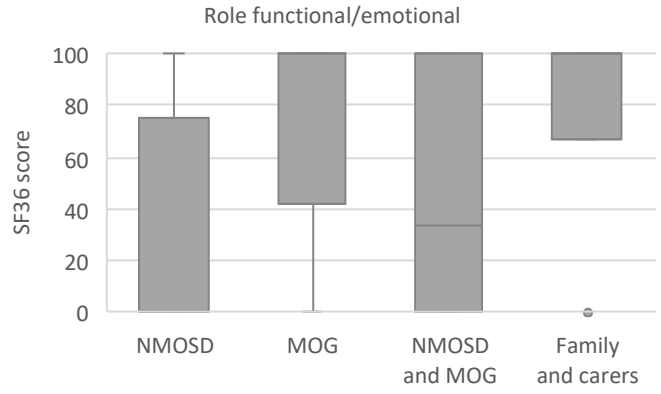

Figure 2.6: Boxplot of SF36 Role functioning/emotional by participant type

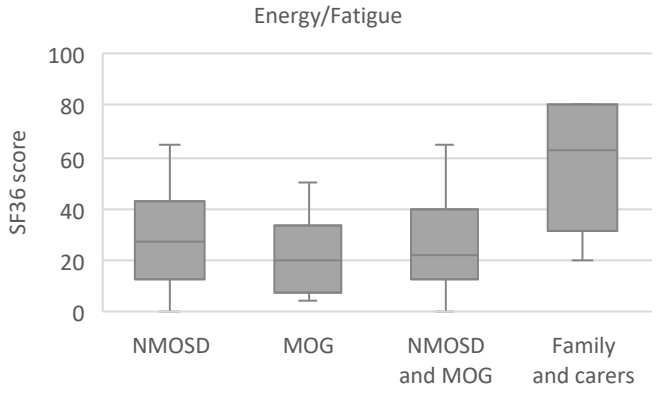

Figure 2.7: Boxplot of SF36 Energy/fatigue by participant type

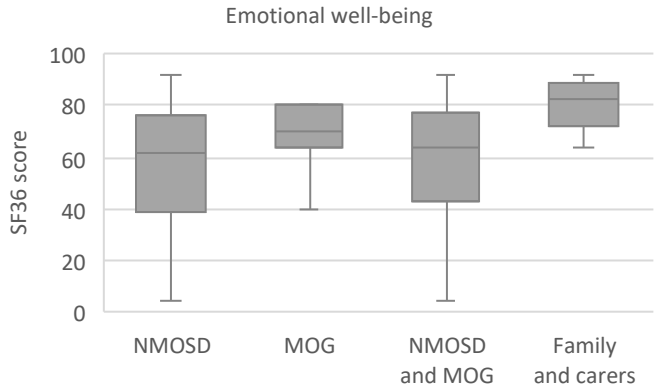

Figure 2.8: Boxplot of SF36 Emotional well-being by participant type

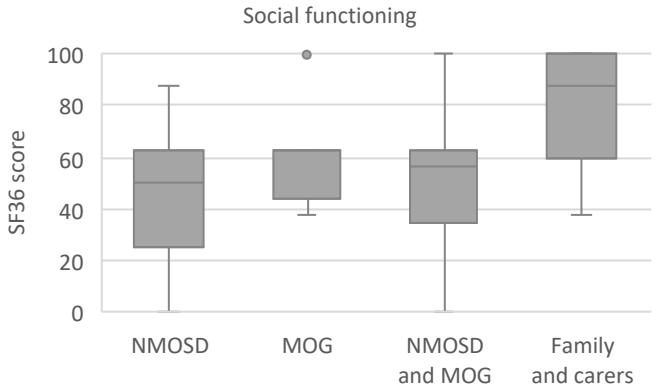

Figure 2.9: Boxplot of SF36 Social functioning by participant type

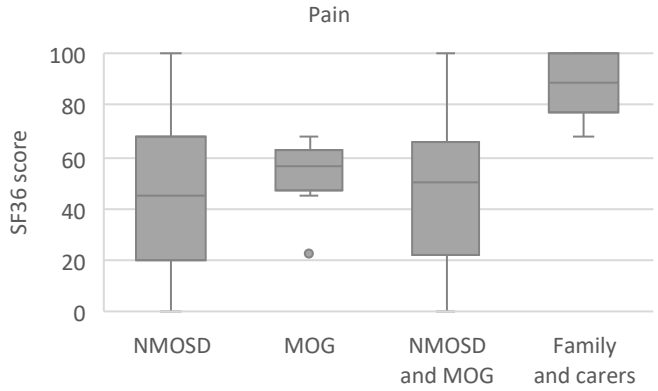

Figure 2.10: Boxplot of SF36 Pain by participant type

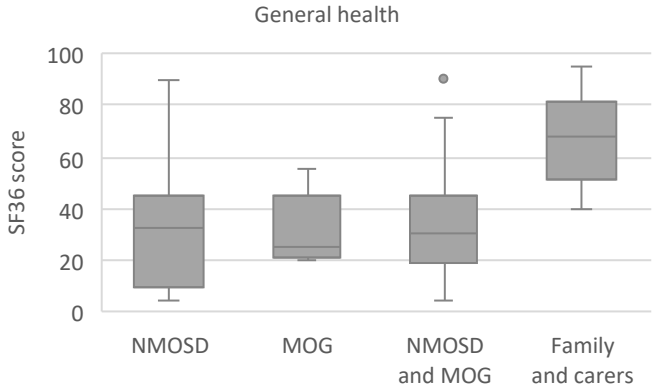

Figure 2.11: Boxplot of SF36 General health by participant type

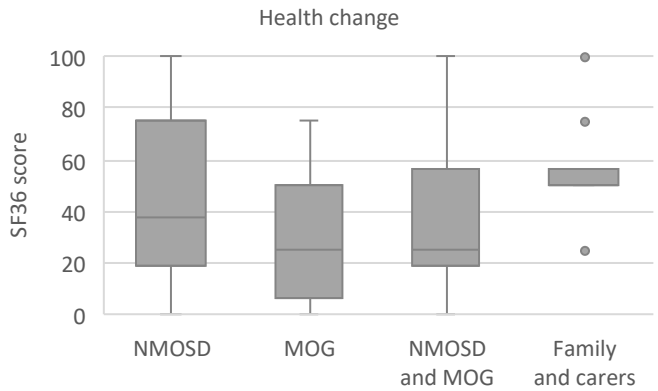

Figure 2.12: Boxplot of SF36 Health change by participant type

Comparisons of SF36 scales by Relapse

Comparisons were made by NMOSD **relapses**, those less than two relapses were included in the *Fewer relapses* subgroup (n=9, 50.00%), and those that had three or more relapses, in the *More relapses* subgroup (n=9, 50.00%). Only participants with NMOSD were included in this comparison.

Boxplots of each SF36 scale by **relapse** are displayed in Figures 2.13 to 2.21, summary statistics are displayed in Tables 2.13 to 2.14. A two-sample t-test was used when assumptions for normality and variance were met (Table 2.13), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.14).

No significant differences were observed between participants in the *Fewer relapses* subgroup compared to those in the *More relapses* subgroup for any of the SF36 scales.

Table 2.13: SF36 by relapse summary statistics and two sample t-test

SF36 scale	Group	Number (n=18)	Percent	Mean	SD	T	dF	p-value
Physical functioning	*Fewer relapses*	9	50.00	52.22	31.24	-0.18	16	0.8603
	More relapses	9	50.00	55.00	34.55			
Energy/Fatigue	*Fewer relapses*	9	50.00	35.00	18.71	1.40	16	0.1796
	More relapses	9	50.00	21.67	21.51			
Emotional well-being	*Fewer relapses*	9	50.00	68.00	23.49	1.92	16	0.0731
	More relapses	9	50.00	47.11	22.70			
Social functioning	*Fewer relapses*	9	50.00	52.78	18.52	0.90	16	0.3815
	More relapses	9	50.00	43.06	26.60			
Pain	*Fewer relapses*	9	50.00	42.78	32.12	-0.04	16	0.9701
	More relapses	9	50.00	43.33	29.82			
General health	*Fewer relapses*	9	50.00	38.33	24.11	1.00	16	0.3339
	More relapses	9	50.00	27.22	23.20			
Health change	*Fewer relapses*	9	50.00	38.89	28.26	-0.49	16	0.6297
	More relapses	9	50.00	47.22	42.29			

Table 2.14: SF36 by relapse summary statistics and Wilcoxon rank sum tests with continuity correction

SF36 scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Role functioning/physical	*Fewer relapses*	9	50.00	0.00	100.00	48.5	0.4233
	More relapses	9	50.00	0.00	0.00		
Role functioning/emotional	*Fewer relapses*	9	50.00	0.00	100.00	48	0.4788
	More relapses	9	50.00	0.00	33.33		

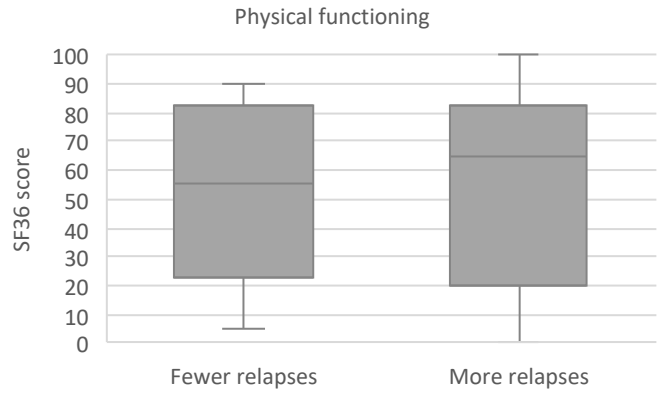

Figure 2.13: Boxplot of SF36 Physical functioning by relapse

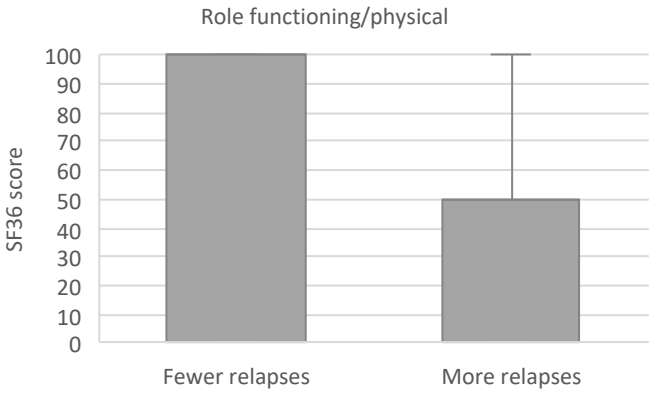

Figure 2.14: Boxplot of SF36 Role functioning/physical by relapse

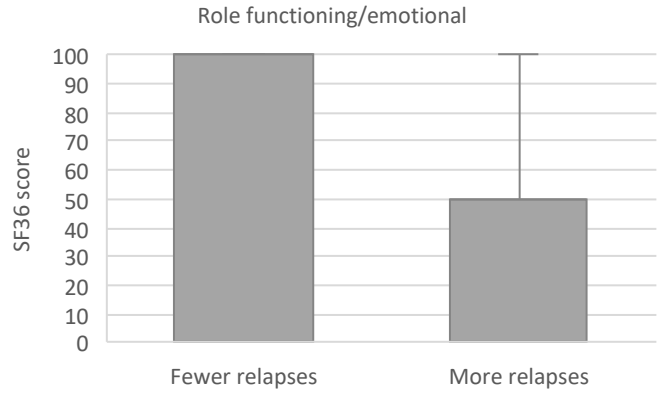

Figure 2.15: Boxplot of SF36 Role functioning/emotional by relapse

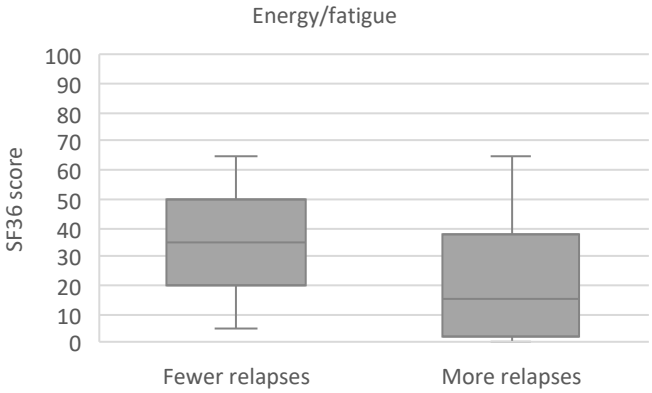

Figure 2.16: Boxplot of SF36 Energy/fatigue by relapse

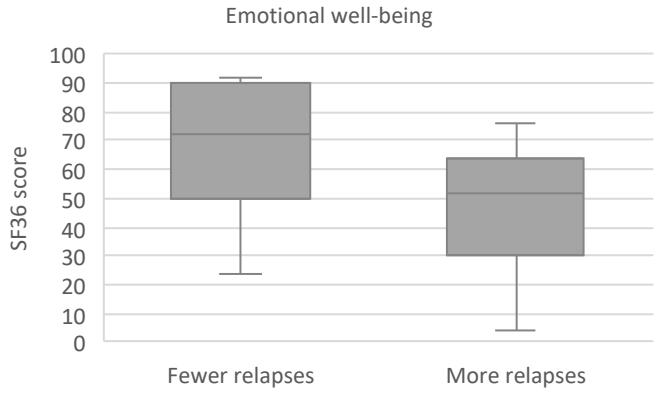

Figure 2.17: Boxplot of SF36 Emotional well-being by relapse

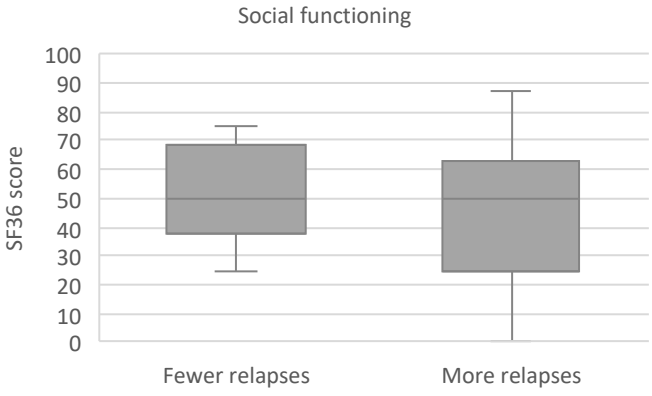

Figure 2.18: Boxplot of SF36 Social functioning by relapse

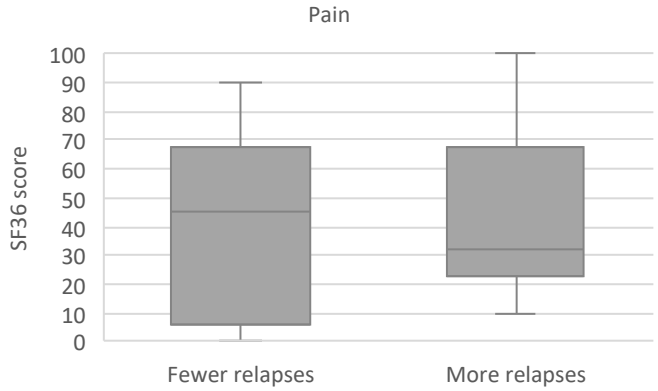

Figure 2.19: Boxplot of SF36 Pain by relapse

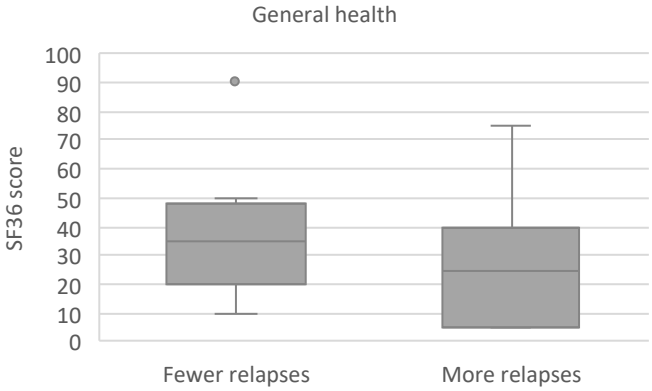

Figure 2.20: Boxplot of SF36 General health by relapse

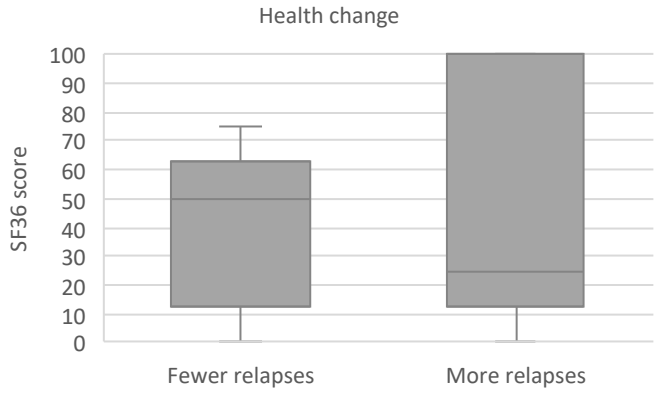

Figure 2.21: Boxplot of SF36 Health change by relapse

Comparisons of SF36 scales by fear of progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Participants that scored over 41 in the **fear of progression** questionnaire were included in the *High to very high fear* subgroup (n=10, 55.56%), and those that scored less than 41 were included in the *Low to moderate fear* subgroup (n=8, 44.44%). Only participants with NMOSD were included in this comparison.

Boxplots of each SF36 scale by **fear of progression** are displayed in Figures 2.22 to 2.30, summary statistics are displayed in Tables 2.15 to 2.16. A two-sample t-test was used when assumptions for normality and variance were met (Table 2.15), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.16).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Role functioning/emotional** [W= 60.00, p=0.0471] was significantly higher for participants in the *Low to moderate fear* subgroup (median=66.67, IQR=100.00) compared to participants in the *High to very high fear* subgroup (median=0.00, IQR =0.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Health change** [W= 64.00, p=0.0325] was significantly higher for participants in the *Low to moderate fear* subgroup (median=62.50, IQR=37.50) compared to participants in the *High to very high fear* subgroup (median=25.00, IQR =43.75).

The **SF36 Role functioning/emotional** scale measures how emotional problems interfere with work or other activities. On average, participants in the *Low to moderate fear* subgroup scored higher than participants in the *High to very high fear* subgroup. This indicates that emotional problems slightly interfered with work or other activities for participants in the *Low to moderate fear* subgroup, compared to extremely interfered with work or other activities for participants in the *High to very high fear* subgroup.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants in the *Low to moderate fear* subgroup scored higher than participants in the *High to very high fear* subgroup. This indicates that participants in subgroup *Low to moderate fear* have health that is somewhat better now than one year ago, compared to participants in the *High to very high fear* subgroup who reported somewhat worse health.

Table 2.15: SF36 by fear of progression summary statistics and two sample t-test

SF36 scale	Group	Number (n=18)	Percent	Mean	SD	T	dF	p-value
Physical functioning	*Low to moderate fear*	8	30.77	63.13	26.31	1.14	16	0.2716
	High to very high fear	10	38.46	46.00	35.34			
Energy/Fatigue	*Low to moderate fear*	8	30.77	36.25	20.13	1.50	16	0.1525
	High to very high fear	10	38.46	22.00	19.89			
Emotional well-being	*Low to moderate fear*	8	30.77	67.00	22.30	1.49	16	0.1548
	High to very high fear	10	38.46	50.00	25.25			
Social functioning	*Low to moderate fear*	8	30.77	54.69	22.10	1.14	16	0.2722
	High to very high fear	10	38.46	42.50	22.97			

*Significant at p<0.005

Table 2.16: SF36 by fear of progression summary statistics and Wilcoxon rank sum tests with continuity correction

SF36 scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Role functioning/physical	*Low to moderate fear*	8	30.77	25.00	100.00	51.00	0.2594
	High to very high fear	10	38.46	0.00	0.00		
Role functioning/emotional	*Low to moderate fear*	8	30.77	66.67	100.00	60.00	0.0471*
	High to very high fear	10	38.46	0.00	0.00		
Pain	*Low to moderate fear*	8	30.77	57.50	22.50	60.00	0.0814
	High to very high fear	10	38.46	22.50	31.25		
General health	*Low to moderate fear*	8	30.77	40.00	17.50	58.00	0.1182
	High to very high fear	10	38.46	20.00	32.50		
Health change	*Low to moderate fear*	8	30.77	62.50	37.50	64.00	0.0325*
	High to very high fear	10	38.46	25.00	43.75		

*Significant at p<0.005

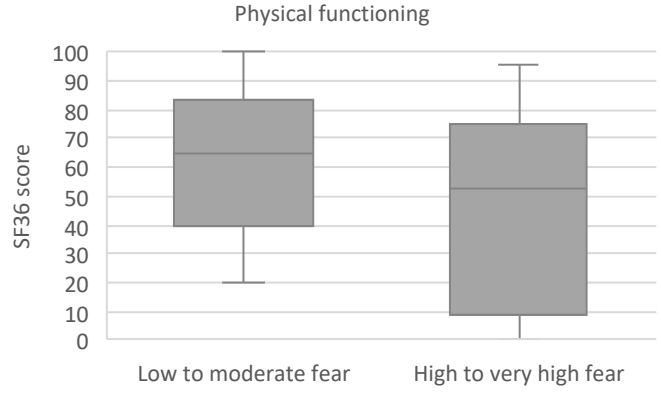

Figure 2.22: Boxplot of SF36 Physical functioning by fear of progression

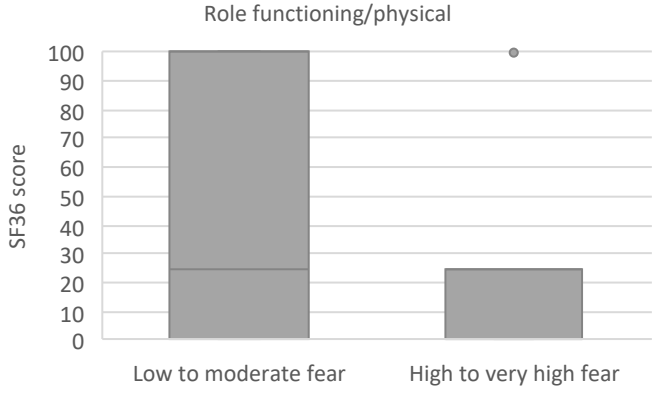

Figure 2.23: Boxplot of SF36 Role functioning/physical by fear of progression

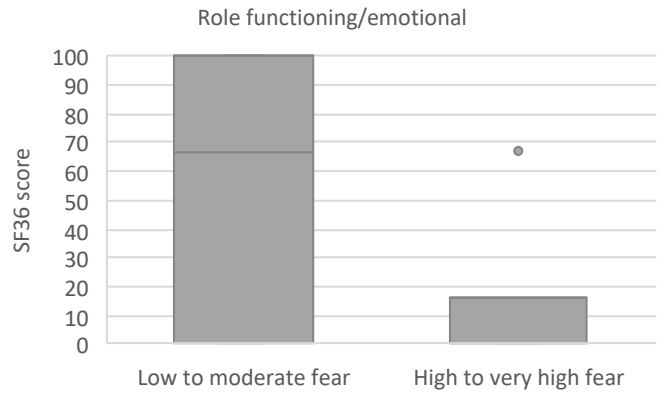

Figure 2.24: Boxplot of SF36 Role functioning/emotional by fear of progression

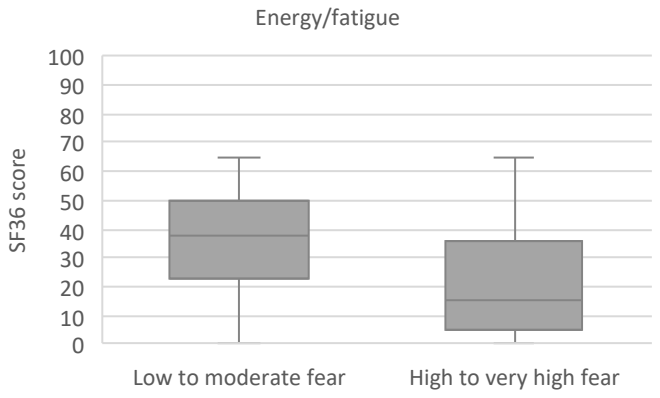

Figure 2.25: Boxplot of SF36 Energy/fatigue by fear of progression

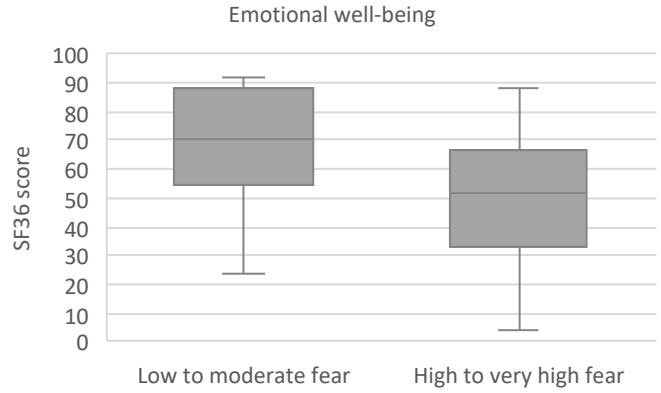

Figure 2.26: Boxplot of SF36 Emotional well-being by fear of progression

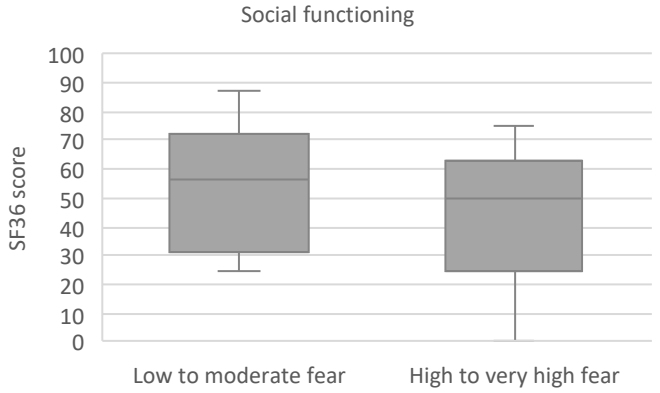

Figure 2.27: Boxplot of SF36 Social functioning by fear of progression

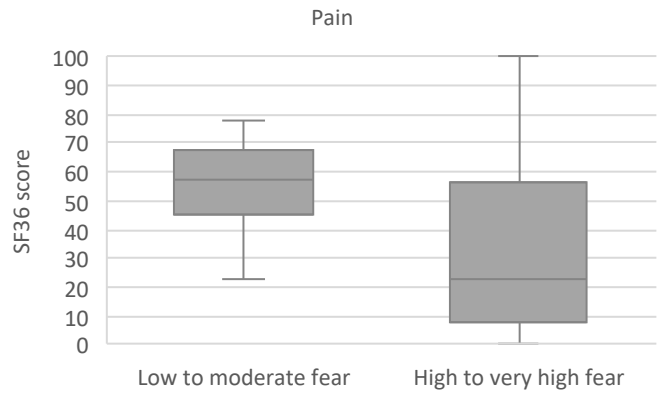

Figure 2.28: Boxplot of SF36 Pain by fear of progression

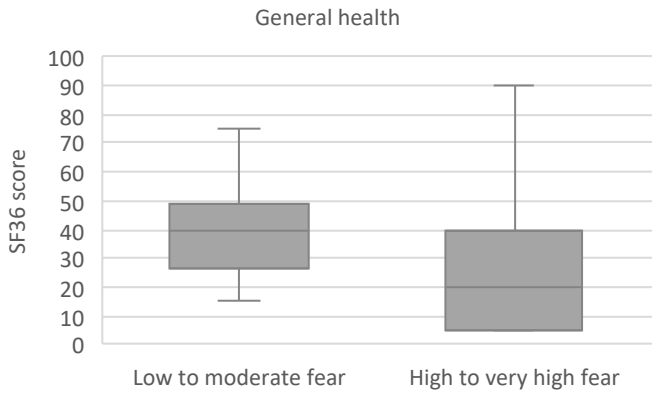

Figure 2.29: Boxplot of SF36 General health by fear of progression

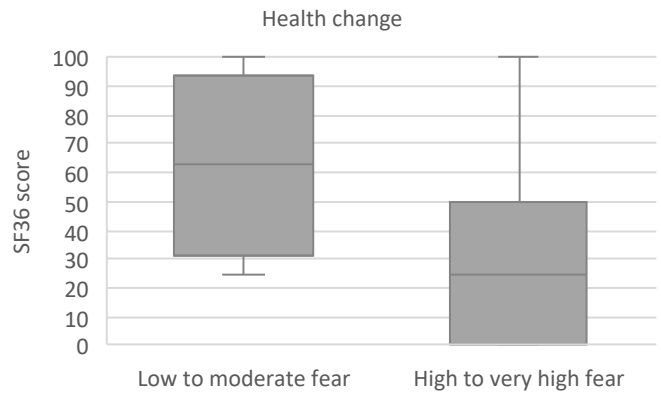

Figure 2.30: Boxplot of SF36 Health change by fear of progression

Comparisons of SF36 scales by physical function

The SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. Comparisons were made by **physical function**, participants that scored in the lowest three quintiles of the SF36 Physical functioning scale were included in the *Moderate to very poor physical function* subgroup (n=9, 50.00%), and participants that scored in the highest two quintiles were included in the *Good to very good physical function* subgroup (n=9, 50.00%). Only participants with NMOSD were included in this comparison.

Boxplots of each SF36 scale by **physical function** are displayed in Figures 2.31 to 2.38, summary statistics are displayed in Tables 2.17 to 2.18. A two-sample t-test was used when assumptions for normality and variance were met (Table 2.17), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.18).

A two sample t-test indicated that the mean score for the **SF36 Energy/fatigue** [t(16) = -2.84 p=0.0118] was significantly higher for participants in the *Good to very good physical function* subgroup (mean =40.00, SD =17.68) compared to participants in the *Moderate to very poor physical function* subgroup (mean = 16.67, SD = 17.14).

A two sample t-test indicated that the mean score for the **SF36 Social functioning** [t(16) = -2.13 p=0.0489]was significantly higher for participants in the *Good to very good physical function* subgroup (mean =58.33, SD =17.68) compared to participants in the *Moderate to very poor physical function* subgroup (mean = 37.50, SD = 23.39)

A two sample t-test indicated that the mean score for the **SF36 Pain** [t(16) = -4.55 p=0.0003] was significantly higher for participants in the *Good to very good physical function* subgroup (mean =65.00, SD =23.28) compared to participants in the *Moderate to very poor physical function* subgroup (mean = 21.11, SD = 17.19).

A two sample t-test indicated that the mean score for the **SF36 Health change** [W= 4.50, p=0.0013] was significantly higher for participants in the *Good to very good physical function* subgroup (mean =65.00, SD =23.28) compared to participants in the *Moderate to very poor physical function* subgroup (mean = 21.11, SD = 17.19).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Health change** [W= 4.50, p=0.0013] was significantly higher for participants in the *Good to very good physical function* subgroup (median =75.00, IQR =50.00) compared to participants in the *Moderate to very poor physical function* subgroup (median = 25.00, IQR = 25.00)

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants in the *Good to very good physical function* subgroup scored higher than participants in the *Moderate to very poor physical function* subgroup. This indicates that participants in the *Good to very good physical function* subgroup tired most of the time, had energy a little of the time, compared participants in the *Moderate to very poor physical function* subgroup who felt tired all of the time.

The **SF36 Social functioning** scale measures **l**imitations on social activities due to physical or emotional problems On average, participants in the *Good to very good physical function* subgroup scored higher than participants in the *Moderate to very poor physical function* subgroup. This indicates that social activities were moderately limited for participants in the *Good to very good physical function* subgroup, compared to social activities were quite limited for participants in the *Moderate to very poor physical function* subgroup.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants in the *Good to very good physical function* subgroup scored higher than participants in the *Moderate to very poor physical function* subgroup. This indicates that participants in the *Good to very good physical function* subgroup had a little pain, compared to participants in the *Moderate to very poor physical function* subgroup, who had a lot of pain.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants in the *Good to very good physical function* subgroup scored higher than participants in the *Moderate to very poor physical function* subgroup. This indicates

that participants in *Good to very good physical function* subgroup have health that is somewhat better now than one year ago, compared to participants in the *Moderate to very poor physical function* who reported somewhat worse health.

Table 2.17: SF36 by physical function summary statistics and two sample t-test

SF36 scale	Group	Number (n=18)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	*Moderate to very poor physical function*	9	50.00	16.67	17.14	-2.84	16	0.0118*
	Good to very good physical function	9	50.00	40.00	17.68			
Emotional well-being	*Moderate to very poor physical function*	9	50.00	46.67	28.28	-2.02	16	0.0604
	Good to very good physical function	9	50.00	68.44	15.68			
Social functioning	*Moderate to very poor physical function*	9	50.00	37.50	23.39	-2.13	16	0.0489*
	Good to very good physical function	9	50.00	58.33	17.68			
Pain	*Moderate to very poor physical function*	9	50.00	21.11	17.19	-4.55	16	0.0003*
	Good to very good physical function	9	50.00	65.00	23.28			
General health	*Moderate to very poor physical function*	9	50.00	22.22	16.79	-2.07	16	0.0552
	Good to very good physical function	9	50.00	43.33	25.62			

*Significant at p<0.005

Table 2.18: SF36 by physical function summary statistics and Wilcoxon rank sum tests with continuity correction

SF36 scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Role functioning/physical	*Moderate to very poor physical function*	9	50.00	0.00	0.00	23.00	0.0696
	Good to very good physical function	9	50.00	50.00	100.00		
Role functioning/emotional	*Moderate to very poor physical function*	9	50.00	0.00	33.33	33.00	0.4788
	Good to very good physical function	9	50.00	0.00	100.00		
Health change	*Moderate to very poor physical function*	9	50.00	25.00	25.00	4.50	0.0013*
	Good to very good physical function	9	50.00	75.00	50.00		

*Significant at p<0.005

Figure 2.31: Boxplot of SF36 Role functioning/physical by physical function

Figure 2.32: Boxplot of SF36 Role functioning/emotional by physical function

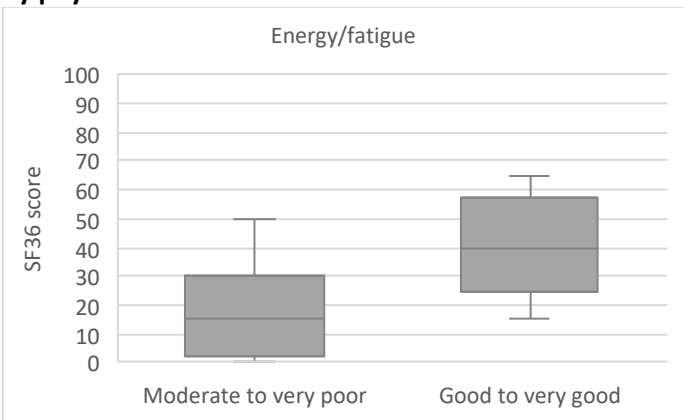

Figure 2.33: Boxplot of SF36 Energy/fatigue by physical function

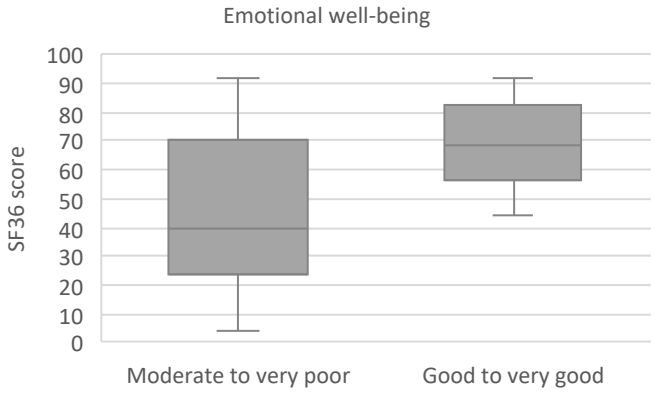

Figure 2.34: Boxplot of SF36 Emotional well-being by physical function

Figure 2.35: Boxplot of SF36 Social functioning by physical function

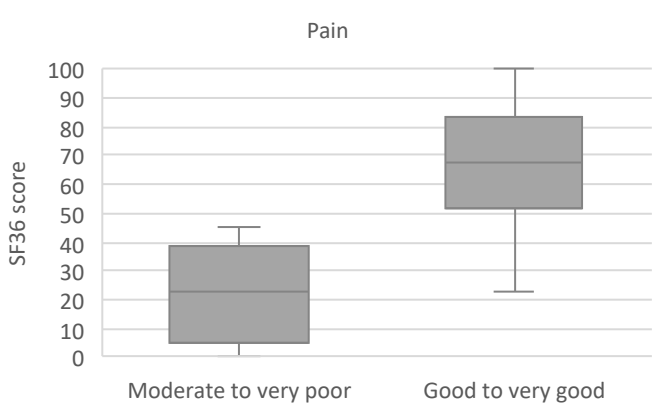

Figure 2.36: Boxplot of SF36 Pain by physical function

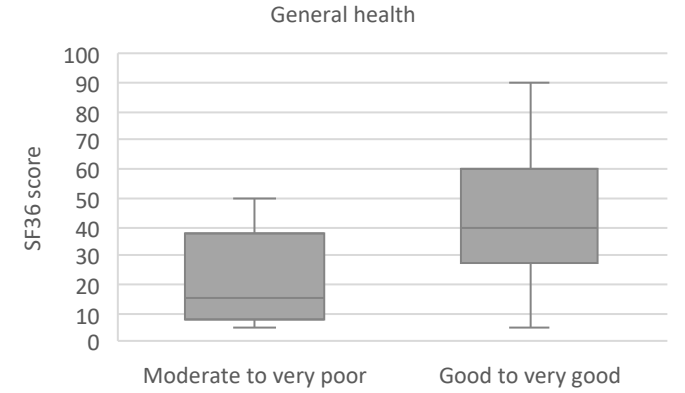

Figure 2.37: Boxplot of SF36 General health by physical function

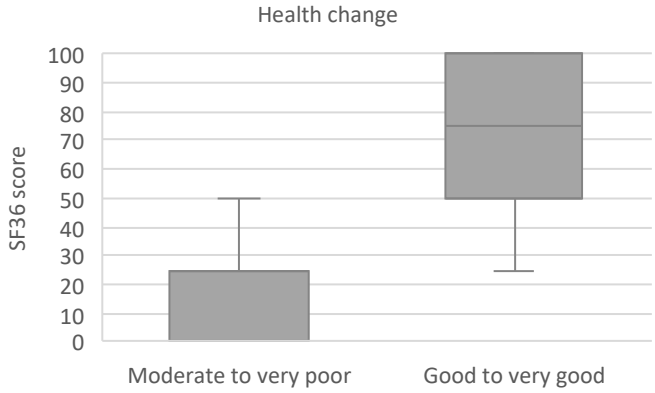

Figure 2.38: Boxplot of SF36 Health change by physical function

Comparisons of SF36 scales by education

Comparisons were made by **education** status, between those with trade or high school qualifications, *trade or high school* (n=10, 55.56%), and those with a university qualification, *University* (n= 8, 44.44%). Only participants with NMOSD were included in this comparison.

Boxplots of each SF36 scale by **education** are displayed in Figures 2.39 to 2.47, summary statistics are displayed in Tables 2.19 to 2.20). A two-sample t-test was used when assumptions for normality and variance were met (Table 2.19), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.20).

A two sample t-test indicated that the mean score for the **SF36 Energy/fatigue** [t(16) = -3.24 p=0.0051] was significantly higher for participants in the *University* subgroup (mean = 42.50, SD = 18.71) compared to participants in the *Trade or high school* subgroup (mean = 17.00, SD = 14.76).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **Role functioning/physical** [W=19.50, p = 0.0317] was significantly higher for participants in the *University* subgroup (Median = 75.00, IQR = 100.00) compared to participants in the *Trade or high school* subgroup (Median = 0.00, SD=0.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **Role functioning/emotional** [W=18.50, p = 0.0325] was significantly higher for participants in the *University* subgroup (Median = 83.33, IQR = 100.00) compared to participants in the *Trade or high school* subgroup (Median = 0.00, SD = 0.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **General health** [W=14.00, p = 0.0228] was significantly higher for participants in the *University* subgroup (Median = 45.00, IQR = 23.75) compared to participants in the *Trade or high school* subgroup (Median = 22.50, SD = 27.50).

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, participants in the *University* subgroup scored higher than participants in the *Trade or high school* subgroup. This indicates that physical health interfered a little with work or other activities for participants in *University* subgroup, compared to extremely interfered with work or other activities for participants in the *Trade or high school* subgroup.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities On average, participants in the *University* subgroup scored higher than participants in the *Trade or high school* subgroup. This indicates that emotional problems did not at all interfere with work or other activities for participants in the *University* subgroup, compared to extremely interfered with work or other activities for participants in the *Trade or high school* subgroup.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants in the *University* subgroup scored higher than participants in the *Trade or high school* subgroup. This indicates that participants in the *University* subgroup felt tired some of the time and had energy some of the time, compared to participants in *Trade or high school* subgroup who felt tired all of the time.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants in the *University* subgroup scored higher than participants in the *Trade or high school* subgroup. This indicates that participants in *University* subgroup have health that is about the same now as one year ago, compared to participants in the *Trade or high school* subgroup who reported somewhat worse health.

Table 2.19: SF36 by education summary statistics and two sample t-test

SF36 scale	Group	Number (n=18)	Percent	Mean	SD	T	dF	p-value
Physical functioning	*Trade or high school*	10	55.56	41.00	33.48	-2.04	16	0.0587
	University	8	44.44	69.38	23.06			
Energy/Fatigue	*Trade or high school*	10	55.56	17.00	14.76	-3.24	16	0.0051*
	University	8	44.44	42.50	18.71			
Emotional well-being	*Trade or high school*	10	55.56	48.00	22.55	-1.97	16	0.0661
	University	8	44.44	69.50	23.51			
Social functioning	*Trade or high school*	10	55.56	40.00	20.24	-1.74	16	0.1003
	University	8	44.44	57.81	23.09			
Pain	*Trade or high school*	10	55.56	33.50	30.17	-1.57	16	0.1357
	University	8	44.44	55.00	27.06			
Health change	*Trade or high school*	10	55.56	32.50	33.44	-1.47	16	0.1603
	University	8	44.44	56.25	34.72			

*Significant at p<0.005

Table 2.20: SF36 by education summary statistics and Wilcoxon rank sum tests with continuity correction

SF36 scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Role functioning/physical	*Trade or high school*	10	55.56	0.00	0.00	19.50	0.0317*
	University	8	44.44	75.00	100.00		
Role functioning/emotional	*Trade or high school*	10	55.56	0.00	0.00	18.50	0.0325*
	University	8	44.44	83.33	100.00		
General health	*Trade or high school*	10	55.56	22.50	27.50	14.00	0.0228*
	University	8	44.44	45.00	23.75		

*Significant at p<0.005

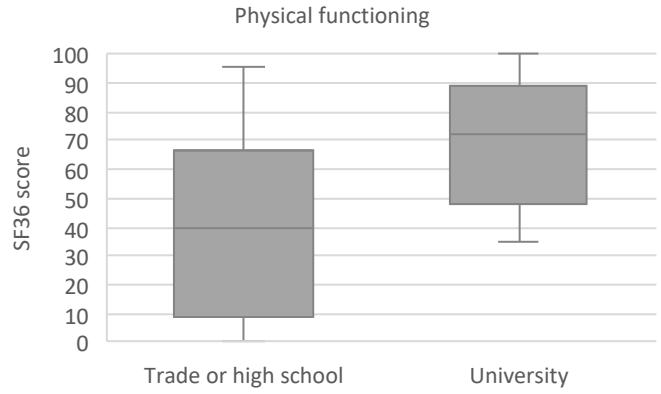

Figure 2.39: Boxplot of SF36 Physical functioning by education

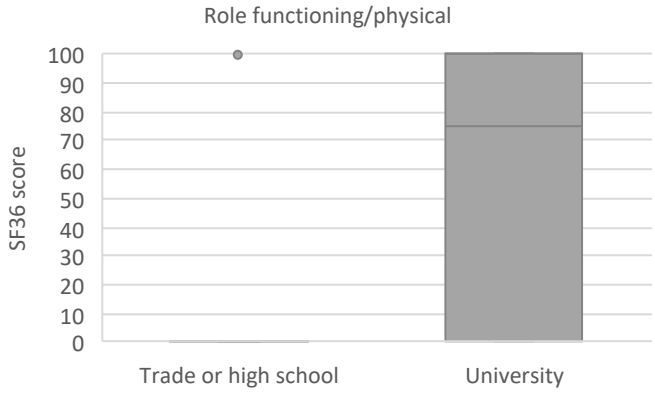

Figure 2.40: Boxplot of SF36 Role functioning/physical by education

Figure 2.41: Boxplot of SF36 Role functioning/emotional by education

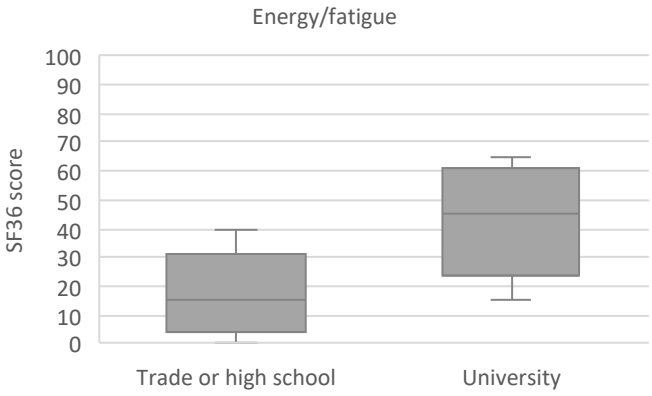

Figure 2.42: Boxplot of SF36 Energy/fatigue by education

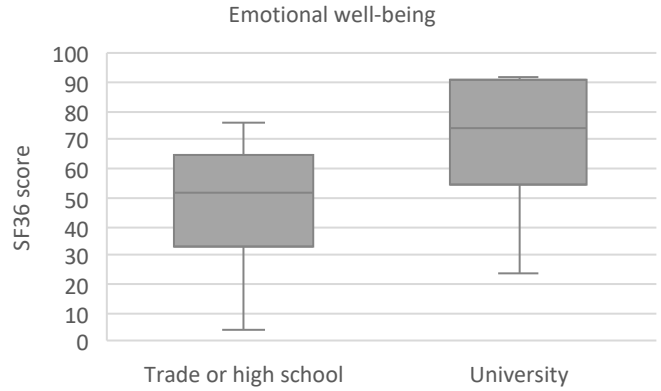

Figure 2.43: Boxplot of SF36 Emotional well-being by education

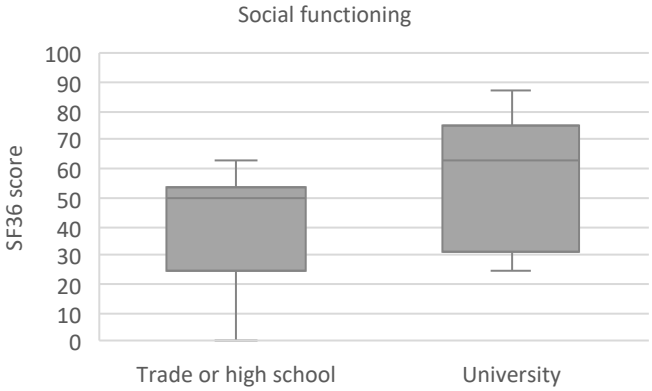

Figure 2.44: Boxplot of SF36 Social functioning by education

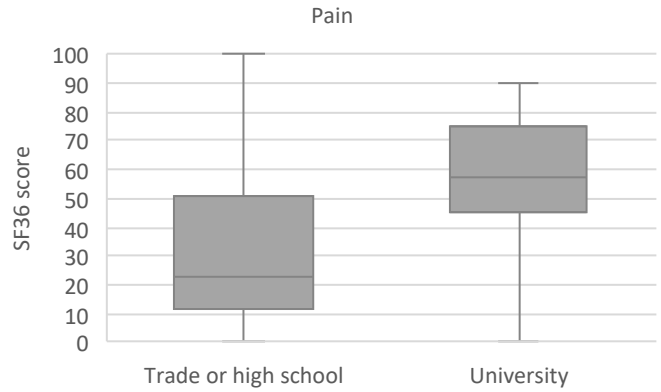

Figure 2.45: Boxplot of SF36 Pain by education

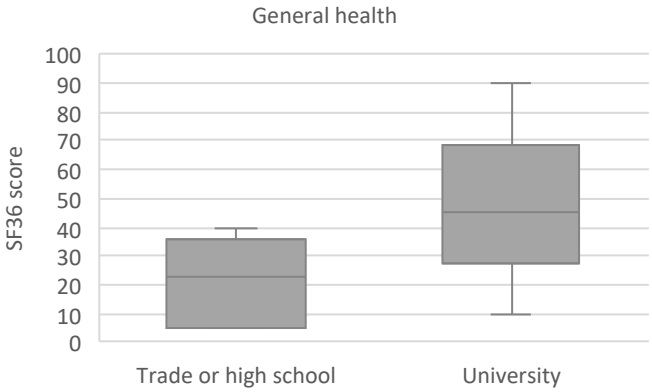

Figure 2.46: Boxplot of SF36 General health by education

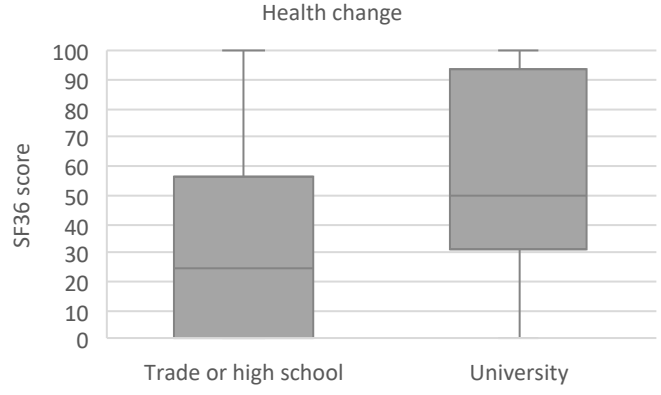

Figure 2.47: Boxplot of SF36 Health change by education

Comparisons of SF36 scales by socioeconomic status

Comparisons were made by **socioeconomic status**, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, *Mid to low status* (n=6, 33.33%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n=12, 66.67%) . Only participants with NMOSD were included in this comparison.

Boxplots of each SF36 scale by **socioeconomic status** are displayed in Figures 2.48 to 2.56, summary statistics are displayed in Tables 2.21 to 2.22. A two-sample t-test was used when assumptions for normality and variance were met (Table 2.21), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.22).

No significant differences were observed between participants in the *Mid to low status* subgroup compared to those in the *Higher status* subgroup for any of the SF36 scales.

Table 2.21: SF36 by socioeconomic status summary statistics and two sample t-test

SF36 scale	Group	Number (n=18)	Percent	Mean	SD	T	dF	p-value
Physical functioning	*Aged 18 to 44*	8	44.44	55.63	36.59	0.23	16	0.8193
	Aged 45 or older	10	55.56	52.00	29.74			
Energy/Fatigue	*Aged 18 to 44*	8	44.44	30.00	21.38	0.30	16	0.7704
	Aged 45 or older	10	55.56	27.00	21.24			
Emotional well-being	*Aged 18 to 44*	8	44.44	49.50	24.74	-1.25	16	0.2292
	Aged 45 or older	10	55.56	64.00	24.22			
Social functioning	*Aged 18 to 44*	8	44.44	40.63	27.35	-1.23	16	0.2355
	Aged 45 or older	10	55.56	53.75	17.73			
Pain	*Aged 18 to 44*	8	44.44	47.50	33.27	0.55	16	0.5904
	Aged 45 or older	10	55.56	39.50	28.55			
General health	*Aged 18 to 44*	8	44.44	30.00	24.05	-0.43	16	0.6695
	Aged 45 or older	10	55.56	35.00	24.38			
Health change	*Aged 18 to 44*	8	44.44	43.75	43.81	0.07	16	0.9429
	Aged 45 or older	10	55.56	42.50	28.99			

Table 2.22: SF36 by socioeconomic status summary statistics and Wilcoxon rank sum tests with continuity correction

SF36 scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Role functioning/physical	*Aged 18 to 44*	8	44.44	0.00	100.00	44.50	0.6674
	Aged 45 or older	10	55.56	0.00	37.50		
Role functioning/emotional	*Aged 18 to 44*	8	44.44	0.00	25.00	33.00	0.5081
	Aged 45 or older	10	55.56	16.67	66.67		

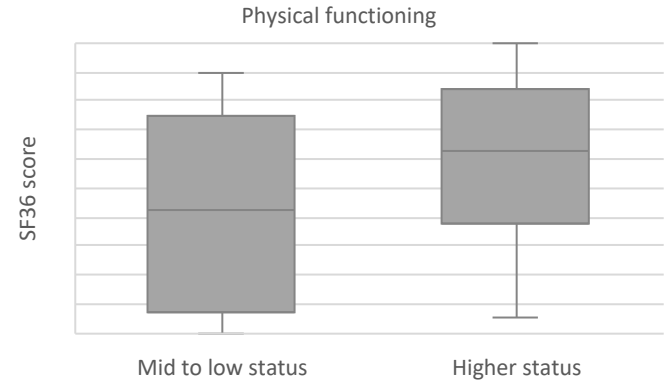

Figure 2.48: Boxplot of SF36 Physical functioning by socioeconomic status

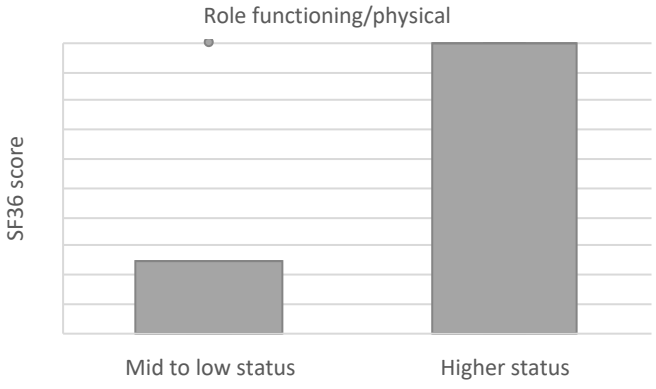

Figure 2.49: Boxplot of SF36 Role functioning/physical by socioeconomic status

Figure 2.50: Boxplot of SF36 Role functioning/emotional by socioeconomic status

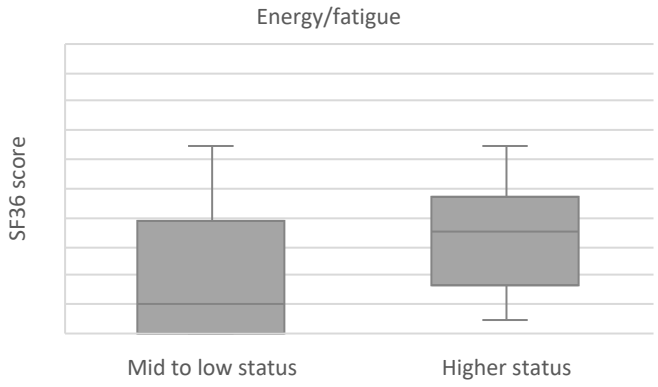

Figure 2.51: Boxplot of SF36 Energy/fatigue by socioeconomic status

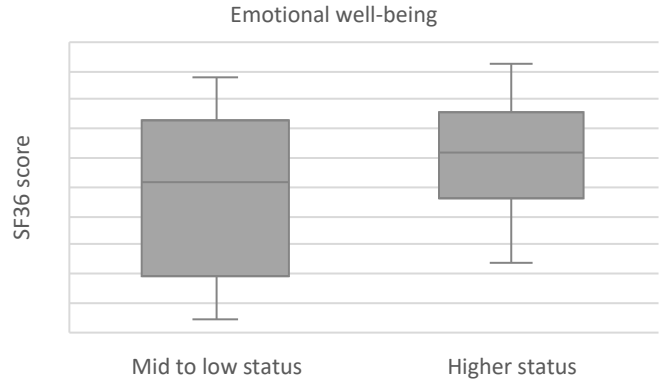

Figure 2.52: Boxplot of SF36 Emotional well-being by socioeconomic status

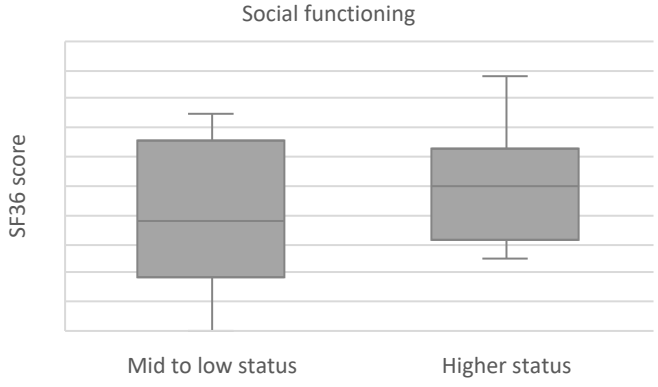

Figure 2.53: Boxplot of SF36 Social functioning by socioeconomic status

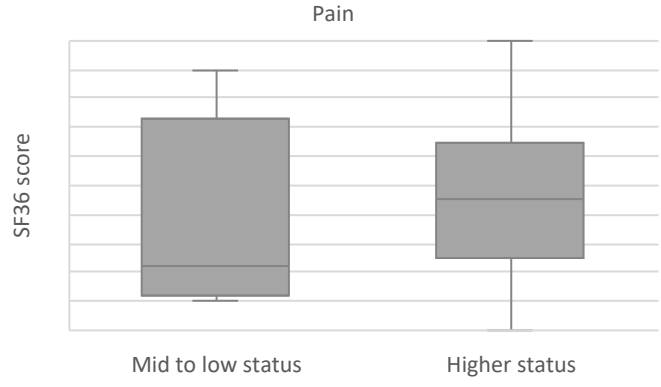

Figure 2.54: Boxplot of SF36 Pain by socioeconomic status

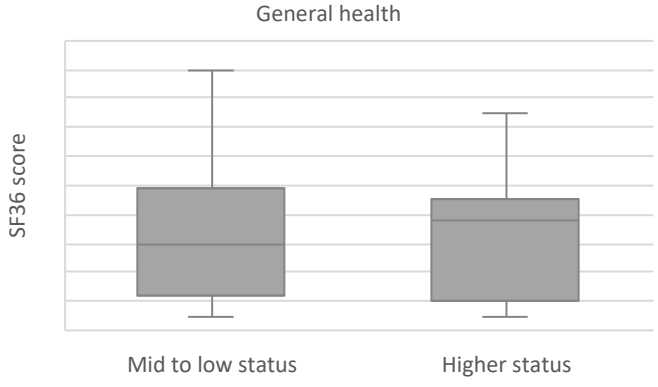

Figure 2.55: Boxplot of SF36 General health by socioeconomic status

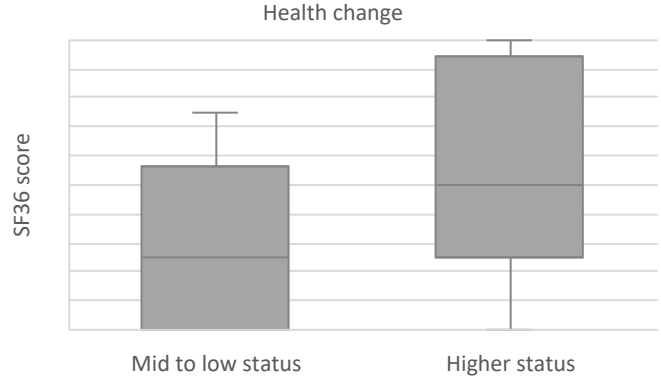

Figure 2.56: Boxplot of SF36 Health change by socioeconomic status

Comparisons of SF36 scales by age

Participants were grouped according to **age,** with comparisons made between participants *Aged 18 to 44* (n=7, 38.89%), , and *Aged 45 or older* (n=11, 61.11%). Only participants with NMOSD were included in this comparison.

Boxplots of each SF36 scale by **age** are displayed in Figures 2.57 to 2.65, summary statistics are displayed in Tables 2.23 to 2.24. A two-sample t-test was used when assumptions for normality and variance were met (Table 2.23), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.24).

No significant differences were observed between participants in the *Aged 18 to 44* subgroup compared to those in the *Aged 45 or older* subgroup for any of the SF36 scales.

Table 2.23: SF36 by age summary statistics and two sample t-test

SF36 scale	Group	Number (n=18)	Percent	Mean	SD	T	dF	p-value
Physical functioning	*Aged 18 to 44*	7	38.89	60.71	36.34	0.74	16	0.4691
	Aged 45 or older	11	61.11	49.09	29.82			
Energy/Fatigue	*Aged 18 to 44*	7	38.89	32.14	22.15	0.61	16	0.5500
	Aged 45 or older	11	61.11	25.91	20.47			
Emotional well-being	*Aged 18 to 44*	7	38.89	47.43	25.97	-1.42	16	0.1749
	Aged 45 or older	11	61.11	64.00	22.98			
Social functioning	*Aged 18 to 44*	7	38.89	42.86	28.74	-0.74	16	0.4692
	Aged 45 or older	11	61.11	51.14	18.92			
Pain	*Aged 18 to 44*	7	38.89	49.64	35.34	0.73	16	0.4752
	Aged 45 or older	11	61.11	38.86	27.17			
General health	*Aged 18 to 44*	7	38.89	28.57	25.61	-0.59	16	0.5633
	Aged 45 or older	11	61.11	35.45	23.18			
Health change	*Aged 18 to 44*	7	38.89	50.00	43.30	0.66	16	0.5203
	Aged 45 or older	11	61.11	38.64	30.34			

Table 2.24: SF36 by age summary statistics and Wilcoxon rank sum tests with continuity correction

SF36 scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Role functioning/physical	*Aged 18 to 44*	7	38.89	0.00	100.00	46.00	0.4434
	Aged 45 or older	11	61.11	0.00	25.00		
Role functioning/emotional	*Aged 18 to 44*	7	38.89	0.00	50.00	35.00	0.7555
	Aged 45 or older	11	61.11	0.00	66.67		

*Significant at p<0.005

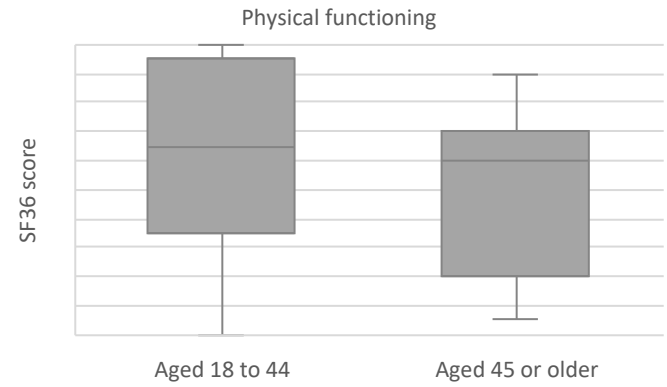

Figure 2.57: Boxplot of SF36 Physical functioning by age

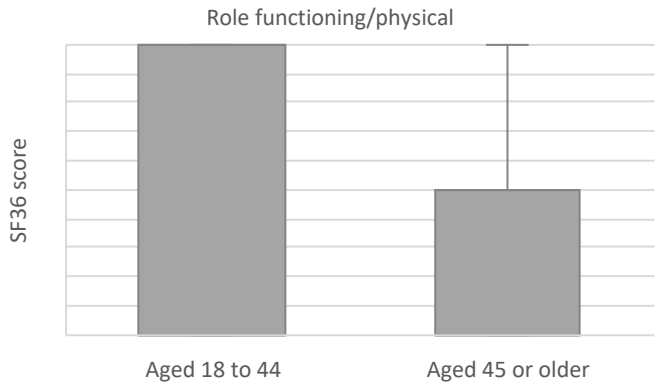

Figure 2.58: Boxplot of SF36 Role functioning/physical by age

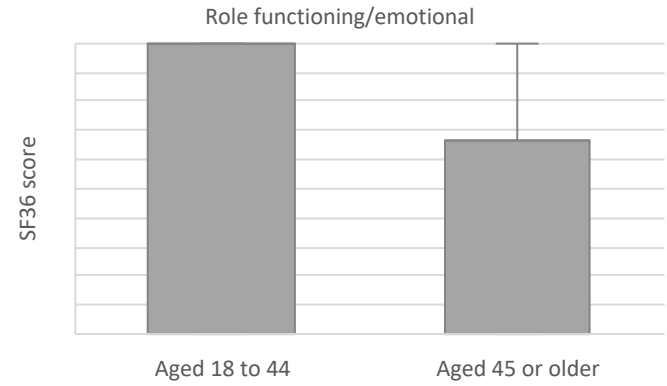

Figure 2.59: Boxplot of SF36 Role functioning/emotional by age

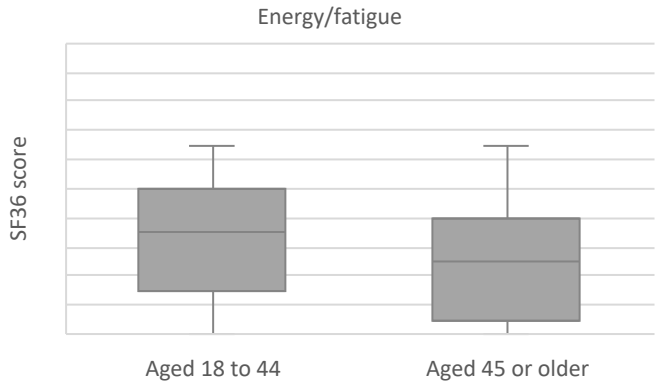

Figure 2.60: Boxplot of SF36 Energy/fatigue by age

Figure 2.61: Boxplot of SF36 Emotional well-being by age

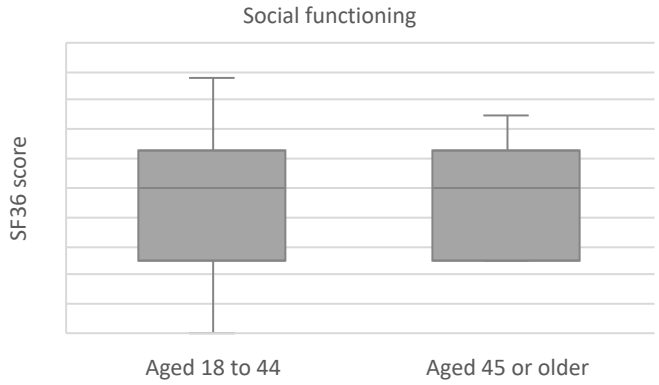

Figure 2.62: Boxplot of SF36 Social functioning by age

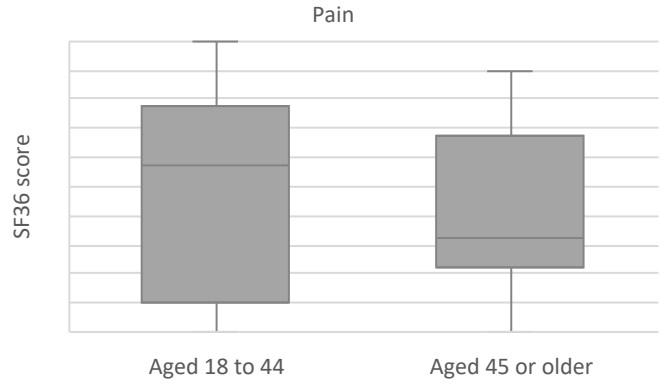

Figure 2.63: Boxplot of SF36 Pain by age

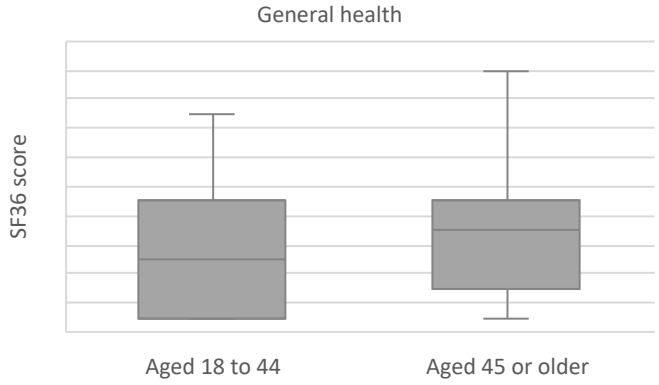

Figure 2.64: Boxplot of SF36 General health by age

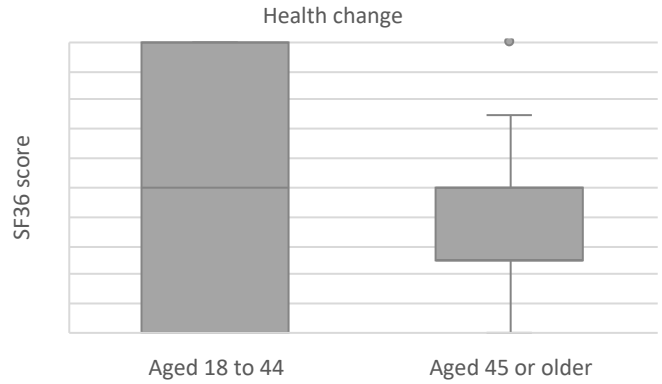

Figure 2.65: Boxplot of SF36 Health change by age

Gender

There were 16 females (n=16, 88.89%) with NMOSD, however, there were too few males (n=2, 11.11%) for comparisons to be made. Data by **gender** is displayed for NMOSD participants in Table 2.25, but no analysis conducted.

Table 2.17: SF36 by gender summary statistics

SF36 scale	Group	Number (n=18)	Percent	Mean	SD	Median	IQR
Physical functioning	*Female*	16	88.89	55.94	32.00	65.00	50.00
	Male	2	11.11	35.00	35.36	35.00	25.00
Role functioning/physical	*Female*	16	88.89	34.38	47.32	0.00	100.00
	Male	2	11.11	0.00	0.00	0.00	0.00
Role functioning/emotional	*Female*	16	88.89	31.25	44.67	0.00	75.00
	Male	2	11.11	33.33	47.14	33.33	33.33
Energy/Fatigue	*Female*	16	88.89	31.25	20.12	32.50	27.50
	Male	2	11.11	5.00	0.00	5.00	0.00
Emotional well-being	*Female*	16	88.89	60.00	25.34	64.00	26.00
	Male	2	11.11	38.00	2.83	38.00	2.00
Social functioning	*Female*	16	88.89	48.44	23.22	50.00	37.50
	Male	2	11.11	43.75	26.52	43.75	18.75
Pain	*Female*	16	88.89	46.25	30.39	45.00	45.00
	Male	2	11.11	17.50	7.07	17.50	5.00
General health	*Female*	16	88.89	34.69	24.05	35.00	31.25
	Male	2	11.11	17.50	17.68	17.50	12.50
Health change	*Female*	16	88.89	46.88	35.21	50.00	50.00
	Male	2	11.11	12.50	17.68	12.50	12.50

Location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. There were 15 participants with NMOSD (83.33%) that lived in *Metropolitan* areas, however, too few participants with NMOSD lived in *Regional or remote* areas (16.67%) for comparisons to be made. Data by **location** is displayed for NMOSD participants throughout the study, but no analysis conducted. Data by **location** is displayed for NMOSD participants in Table 2.26, but no analysis conducted.

Table 2.22: SF36 by location summary statistics

SF36 scale	Group	Number (n=18)	Percent	Mean	SD	Median	IQR
Physical functioning	*Regional or remote*	3	16.67	55.94	32.00	65.00	50.00
	Metropolitan	15	83.33	35.00	35.36	35.00	25.00
Role functioning/physical	*Regional or remote*	16	88.89	34.38	47.32	0.00	100.00
	Metropolitan	2	11.11	0.00	0.00	0.00	0.00
Role functioning/emotional	*Regional or remote*	16	88.89	31.25	44.67	0.00	75.00
	Metropolitan	2	11.11	33.33	47.14	33.33	33.33
Energy/Fatigue	*Regional or remote*	16	88.89	31.25	20.12	32.50	27.50
	Metropolitan	2	11.11	5.00	0.00	5.00	0.00
Emotional well-being	*Regional or remote*	16	88.89	60.00	25.34	64.00	26.00
	Metropolitan	2	11.11	38.00	2.83	38.00	2.00
Social functioning	*Regional or remote*	16	88.89	48.44	23.22	50.00	37.50
	Metropolitan	2	11.11	43.75	26.52	43.75	18.75
Pain	*Regional or remote*	16	88.89	46.25	30.39	45.00	45.00
	Metropolitan	2	11.11	17.50	7.07	17.50	5.00
General health	*Regional or remote*	16	88.89	34.69	24.05	35.00	31.25
	Metropolitan	2	11.11	17.50	17.68	17.50	12.50
Health change	*Regional or remote*	16	88.89	46.88	35.21	50.00	50.00
	Metropolitan	2	11.11	12.50	17.68	12.50	12.50

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Experience of symptoms before diagnosis

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

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

Symptoms leading to diagnosis

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

Symptoms leading to diagnosis: Seeking medical attention

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

Symptoms leading to diagnosis: Diagnostic pathway

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

Symptoms leading to diagnosis: Symptom recall

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

Diagnostic tests

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

Time from diagnostic test to diagnosis

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

Time from symptoms to diagnosis

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

Diagnosis provider and location

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

Form of condition

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

Age at diagnosis

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

Number of relapses

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

Year of diagnosis

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

Understanding of disease at diagnosis

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

Emotional support at diagnosis

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

Information at diagnosis

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

Costs at diagnosis

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

Genetic tests and biomarkers

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

Experience of genetic tests and biomarkers

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

Specific biomarkers or genetic markers

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

Understanding of prognosis

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

Experience of symptoms before diagnosis

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

NMOSD

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

MOG

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

NMOSD and MOG

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

Table 3.1: Number of symptoms before diagnosis

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

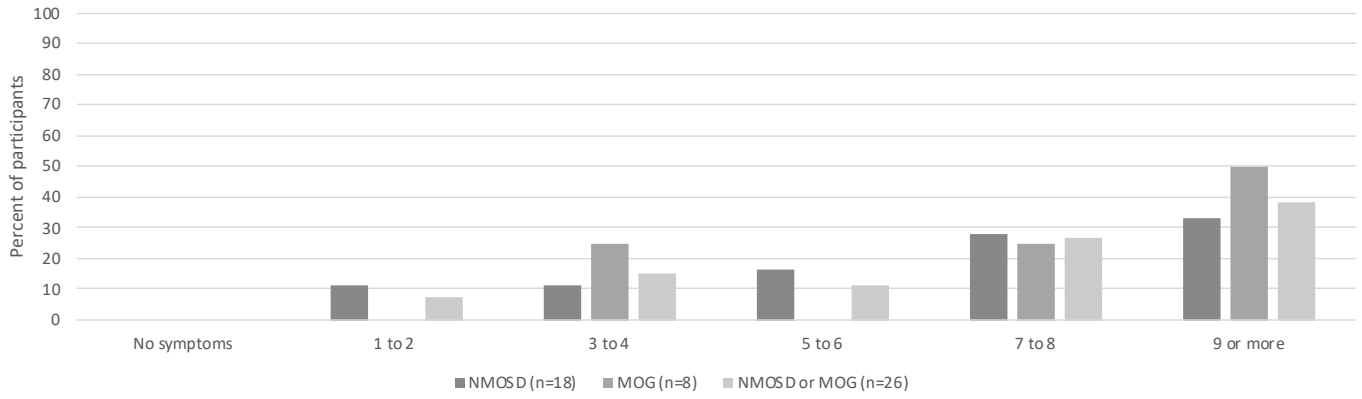

Figure 3.1: Number of symptoms before diagnosis

Symptoms before diagnosis

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

NMOSD

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

MOG

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

NMOSD or MOG

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

Table 3.2: Symptoms before diagnosis

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

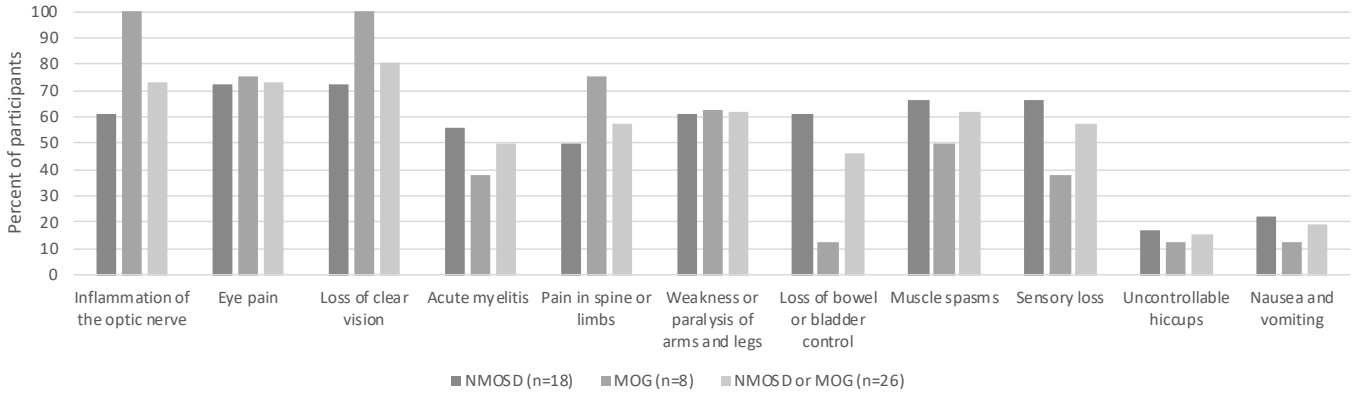

Figure 3.2: Symptoms before diagnosis

Quality of life from symptoms before diagnosis

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

NMOSD

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

MOG

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

NMOSD or MOG

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

Table 3.3: Quality of life from symptoms before diagnosis

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

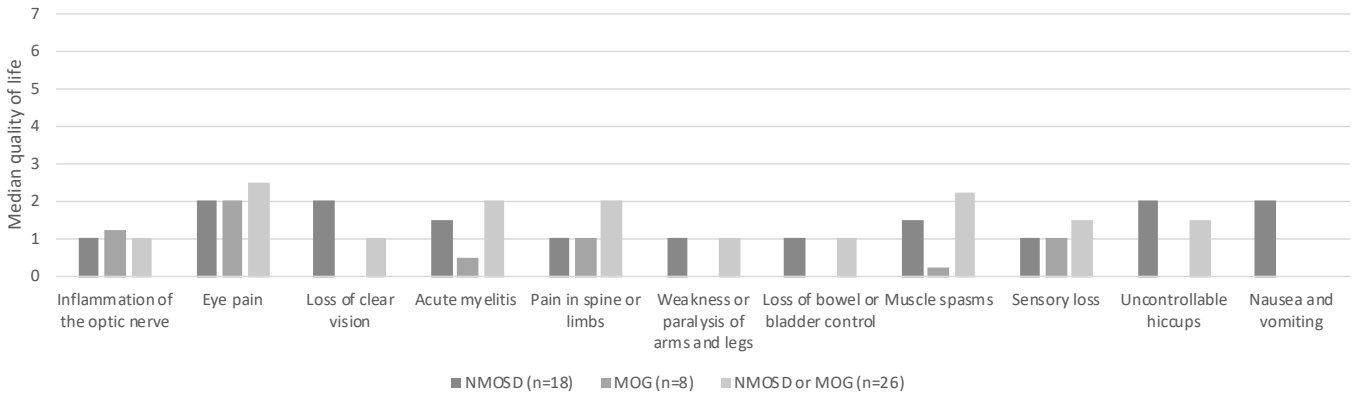

Figure 3.3: Quality of life from symptoms before diagnosis

Symptoms leading to diagnosis

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

Participant describes having visual problems, which led to their diagnosis

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

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

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

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

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

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

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

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

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

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

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

Participant describes having eye pain, which led to their diagnosis

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

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

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

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

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

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

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

Participant describes having fatigue, which led to their diagnosis

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

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

Table 3.4: Symptoms leading to diagnosis

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

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

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

Table 3.5: Symptoms leading to diagnosis (Subgroup variations)

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

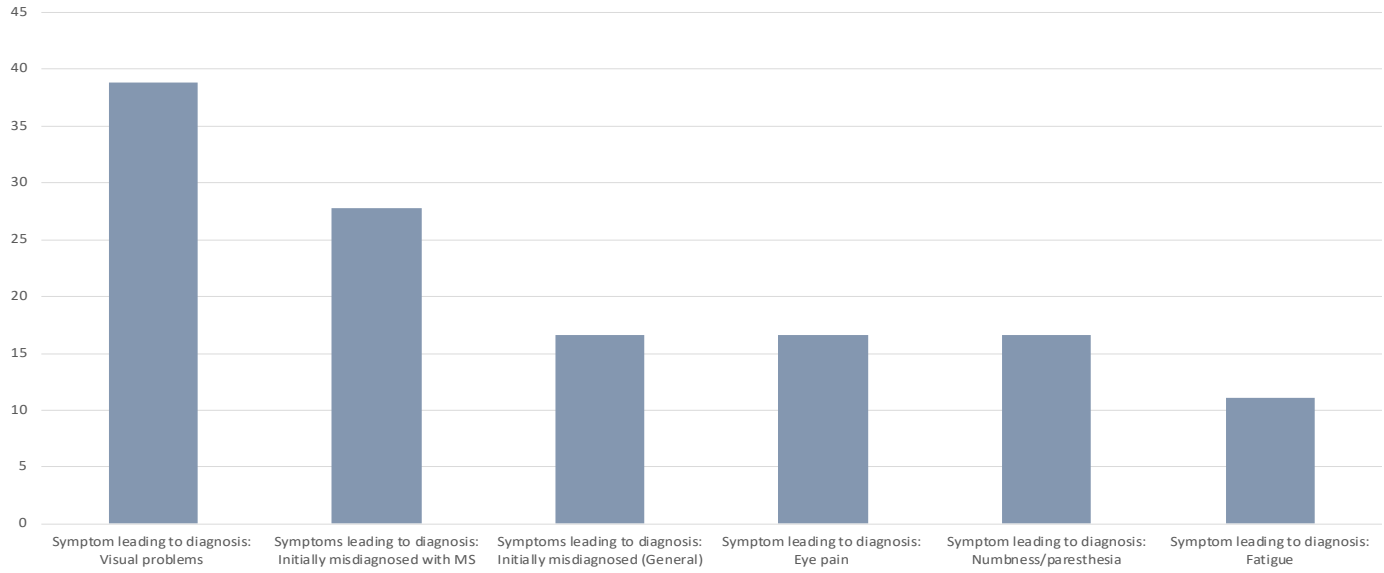

Figure 3.4: Symptoms leading to diagnosis

Symptoms leading to diagnosis: Seeking medical attention

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

Participant describes having symptoms and seeking medical attention relatively soon

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

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

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

Table 3.6: Seeking medical attention

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

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

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

Table 3.7: Seeking medical attention (Subgroup variations)

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

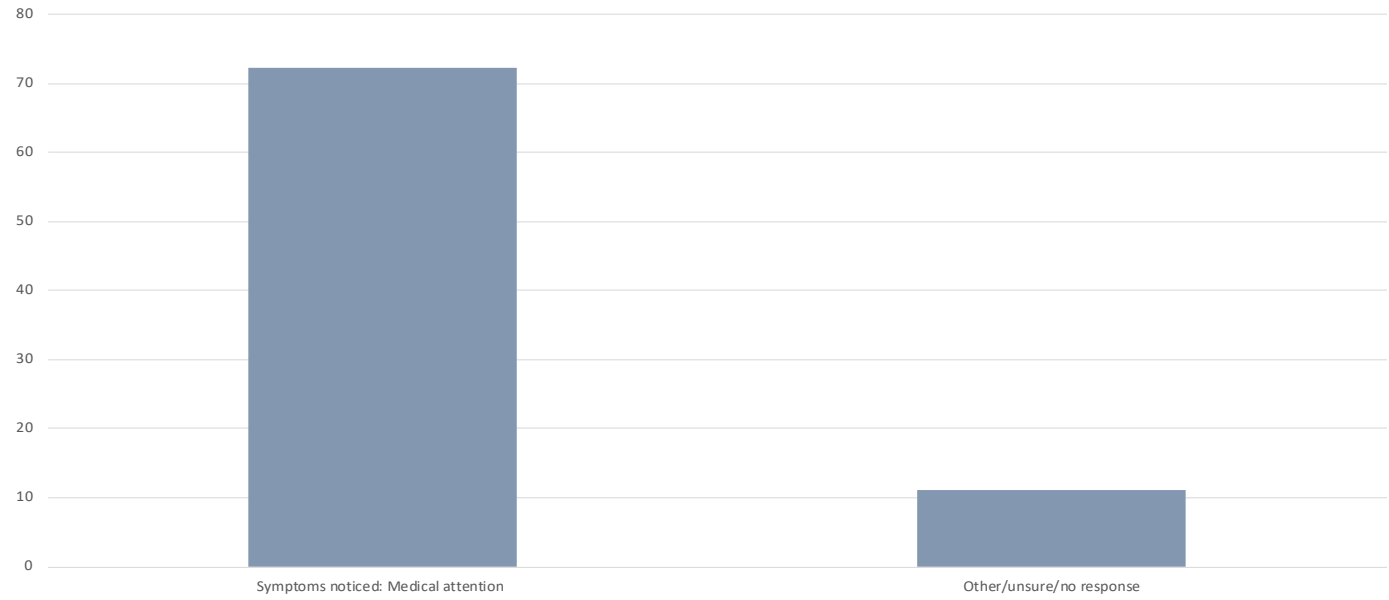

Figure 3.5: Seeking medical attention

Symptoms leading to diagnosis: Diagnostic pathway

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Table 3.8: Symptoms leading to diagnosis: Diagnostic pathway

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

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

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

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

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

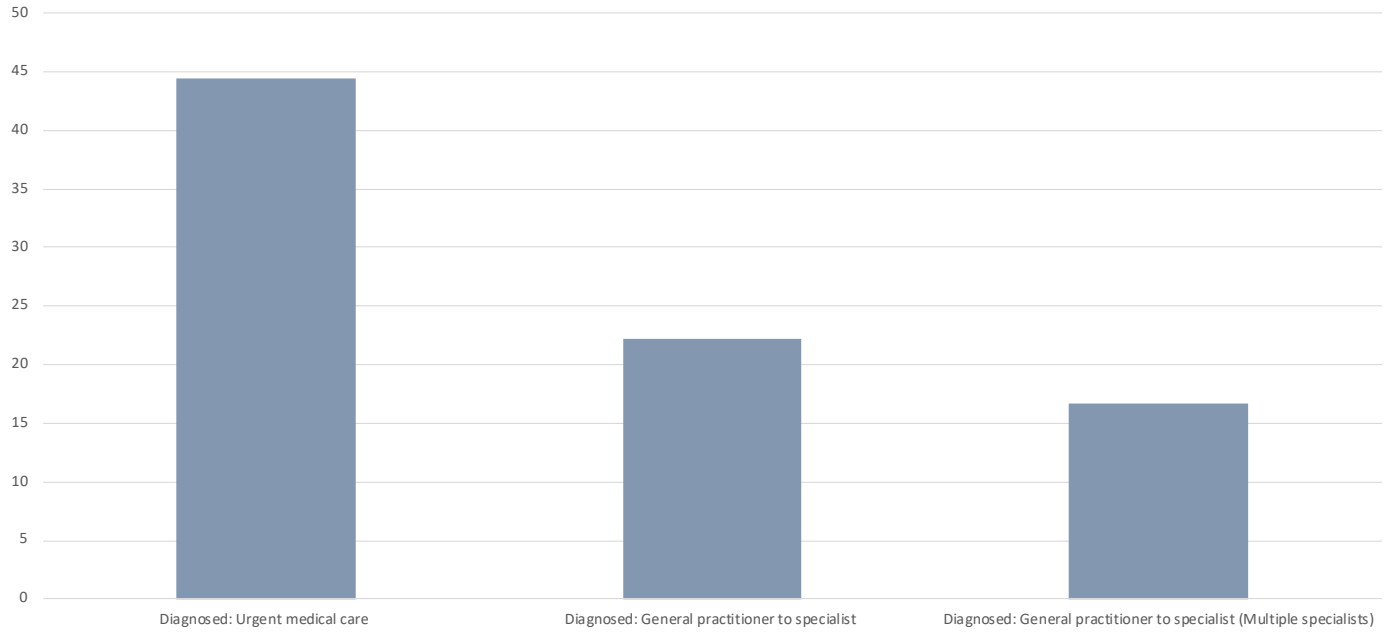

Figure 3.6: Symptoms leading to diagnosis: Diagnostic pathway

Symptoms leading to diagnosis: Symptom recall

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

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

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

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

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

Table 3.10: Symptoms leading to diagnosis: Symptom recall

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

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

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

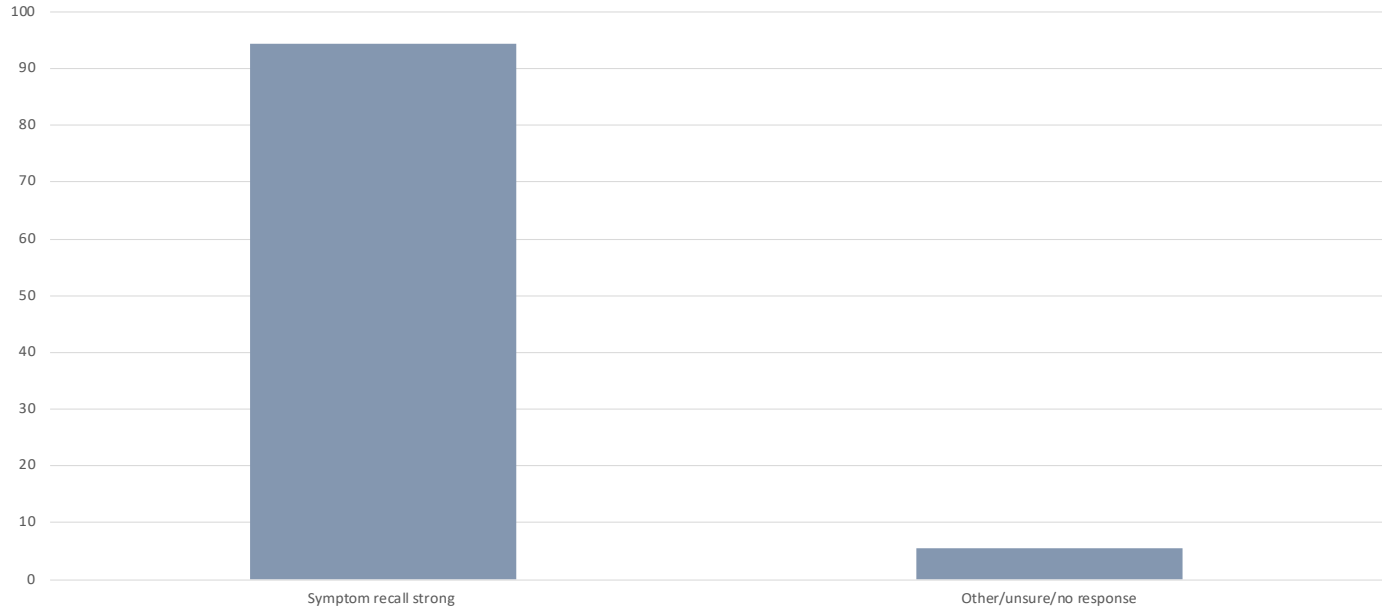

Figure 3.7: Symptoms leading to diagnosis: Symptom recall

Diagnostic tests

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

NMOSD

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

MOG

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

NMOSD or MOG

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

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

Table 3.11: Number of diagnostic tests

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

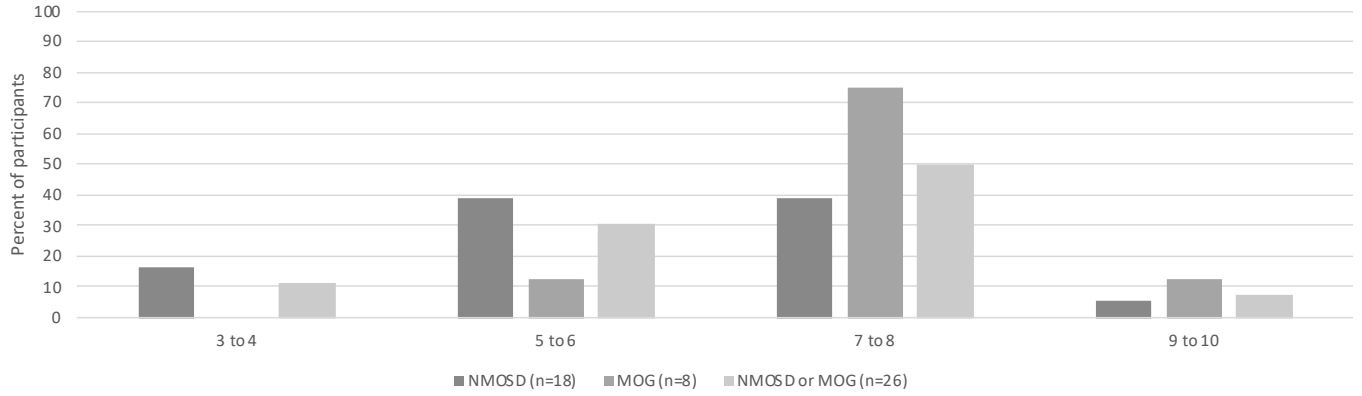

Figure 3.8: Number of diagnostic tests

Table 3.12: Diagnostic tests

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

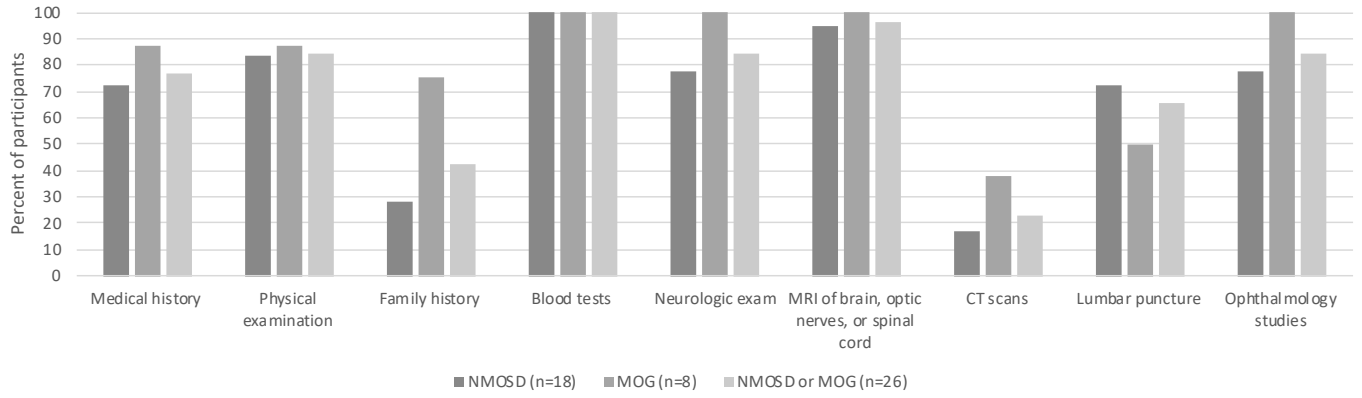

Figure 3.9: Diagnostic tests

Time from diagnostic test to diagnosis

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

NMOSD

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

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

MOG

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

NMOSD or MOG

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

Table 3.13: Time from diagnostic test to diagnosis

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

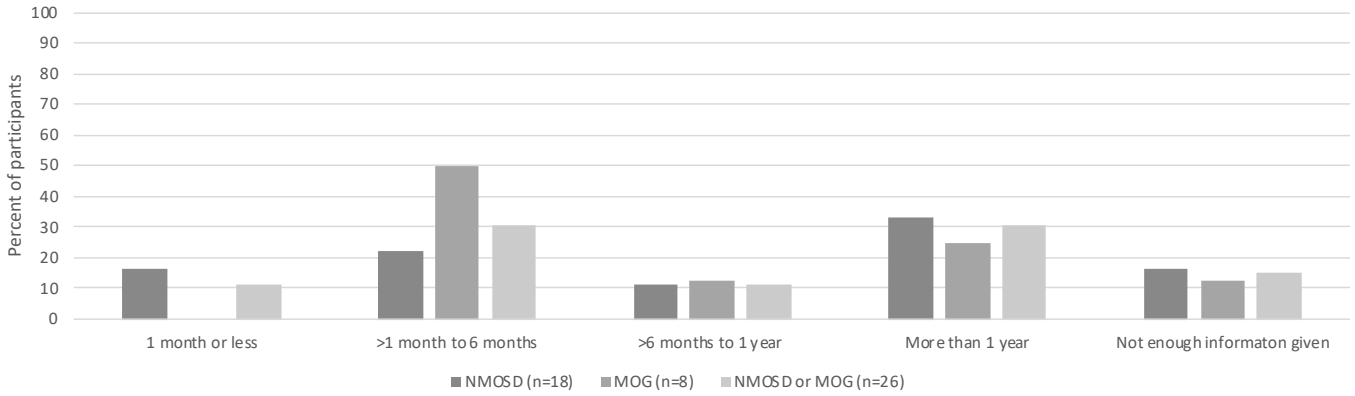

Figure 3.10: Time from diagnostic test to diagnosis

Time from symptoms to diagnosis

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

NMOSD

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

MOG

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

NMOSD or MOG

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

Table 3.14: Time from symptoms to diagnosis

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

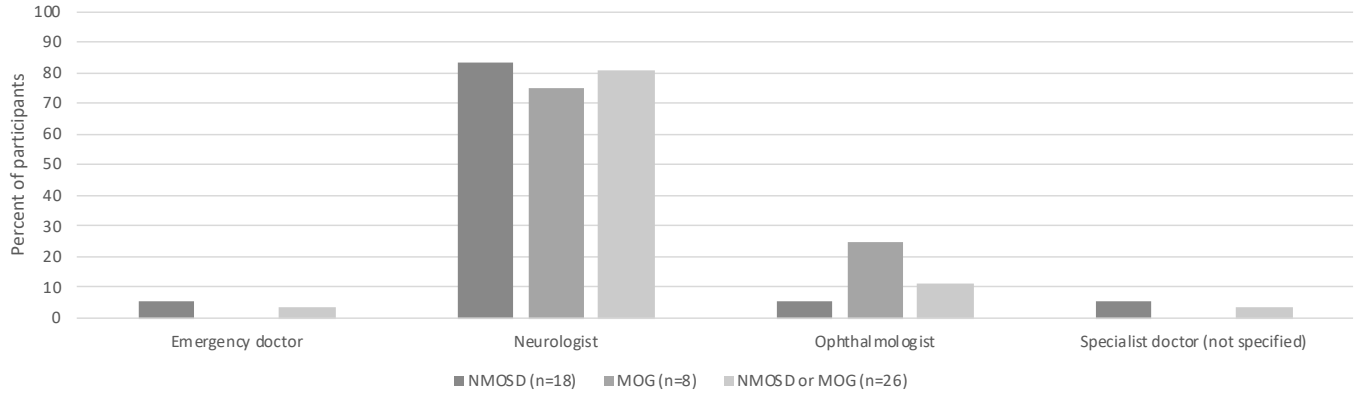

Figure 3.11: Time from symptoms to diagnosis

Diagnosis provider and location

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

NMOSD

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

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

MOG

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

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

NMOSD or MOG

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

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

Table 3.15: Diagnosis provider

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

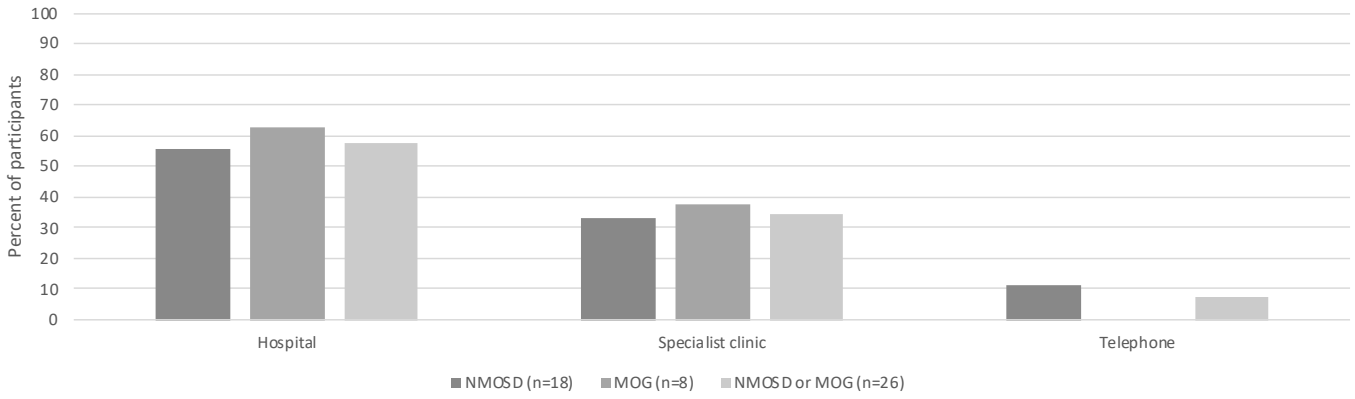

Figure 3.12: Diagnosis provider

Table 3.16: Diagnosis location

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

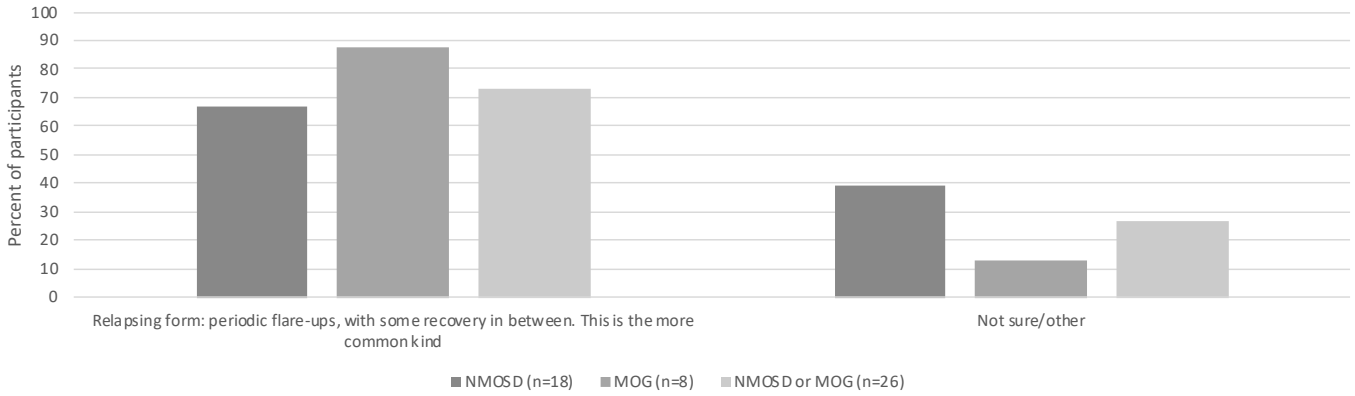

Figure 3.13: Diagnosis location

Form of condition

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

NMOSD

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

MOG

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

NMOSD and MOG

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

Table 3.17: Form of condition

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

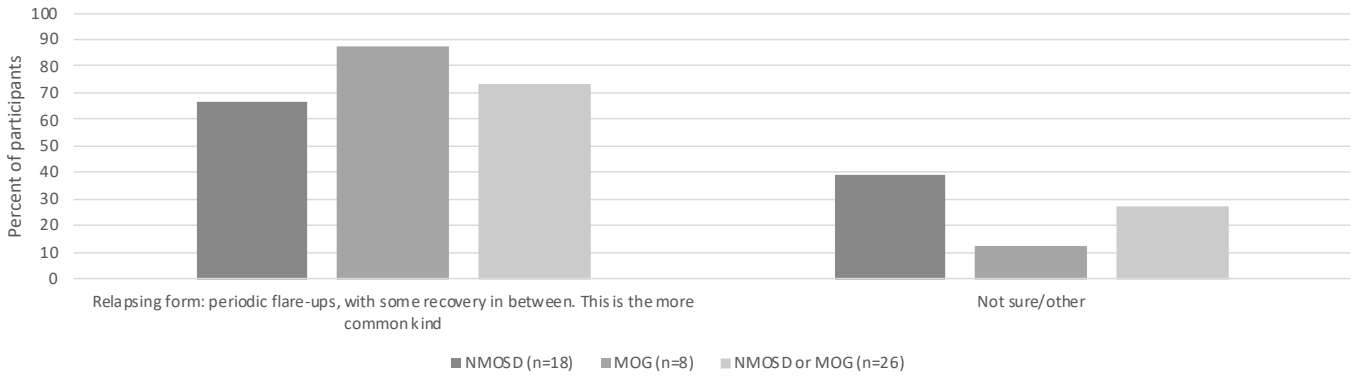

Figure 3.14: Form of condition

Age at diagnosis

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

NMOSD

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

MOG

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

NMOSD or MOG

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

Table 3.18: Age at diagnosis

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

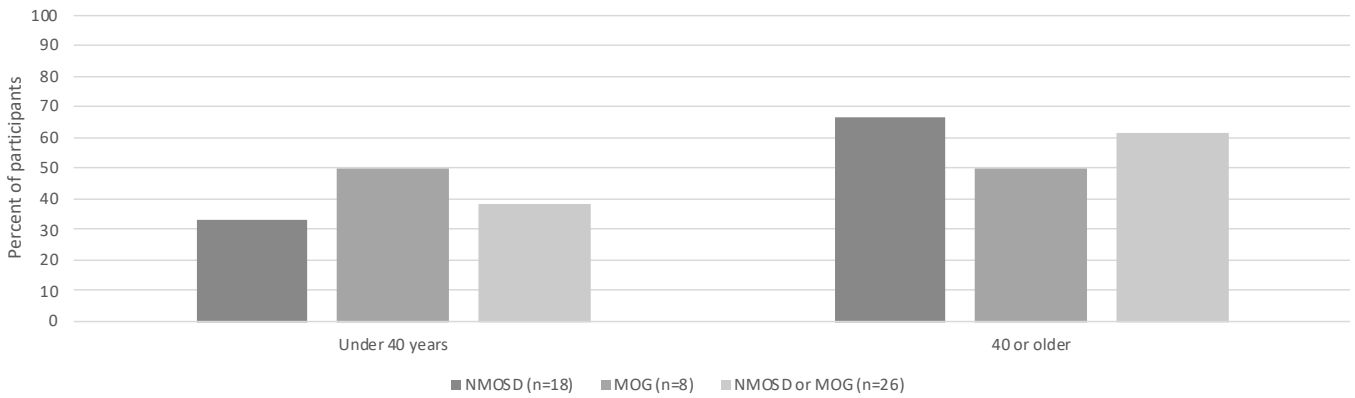

Figure 3.15: Age at diagnosis

Number of relapses

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

NMOSD

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

MOG

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

NMOSD or MOG

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

Table 3.19: Number of relapses

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

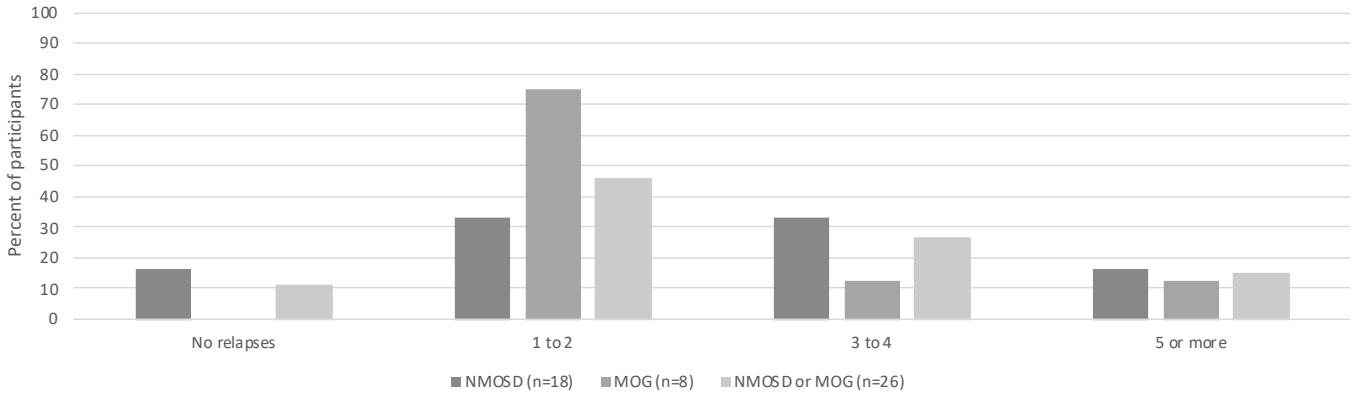

Figure 3.16: Number of relapses

Year of diagnosis

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

NMOSD

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

MOG

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

NMOSD and MOG

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

Table 3.20: Year of diagnosis

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

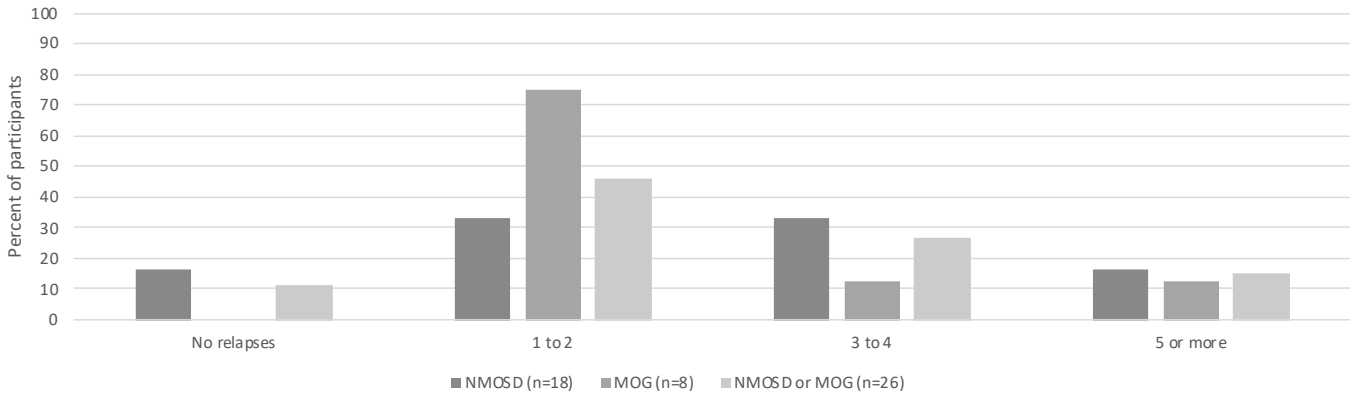

Figure 3.17: Year of diagnosis

Understanding of disease at diagnosis

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

Participant describes knowing nothing about the condition at diagnosis

Absolutely nothing. Participant NMO_010

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

I knew nothing about it. Participant NMO_008

Participant describes knowing very little about the condition at diagnosis

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

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

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

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

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

I knew nothing about it. Participant NMO_008

Nothing. Absolutely nothing. Participant NMOCA_007

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

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

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

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

Table 3.21: Understanding of disease at diagnosis

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

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

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

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

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

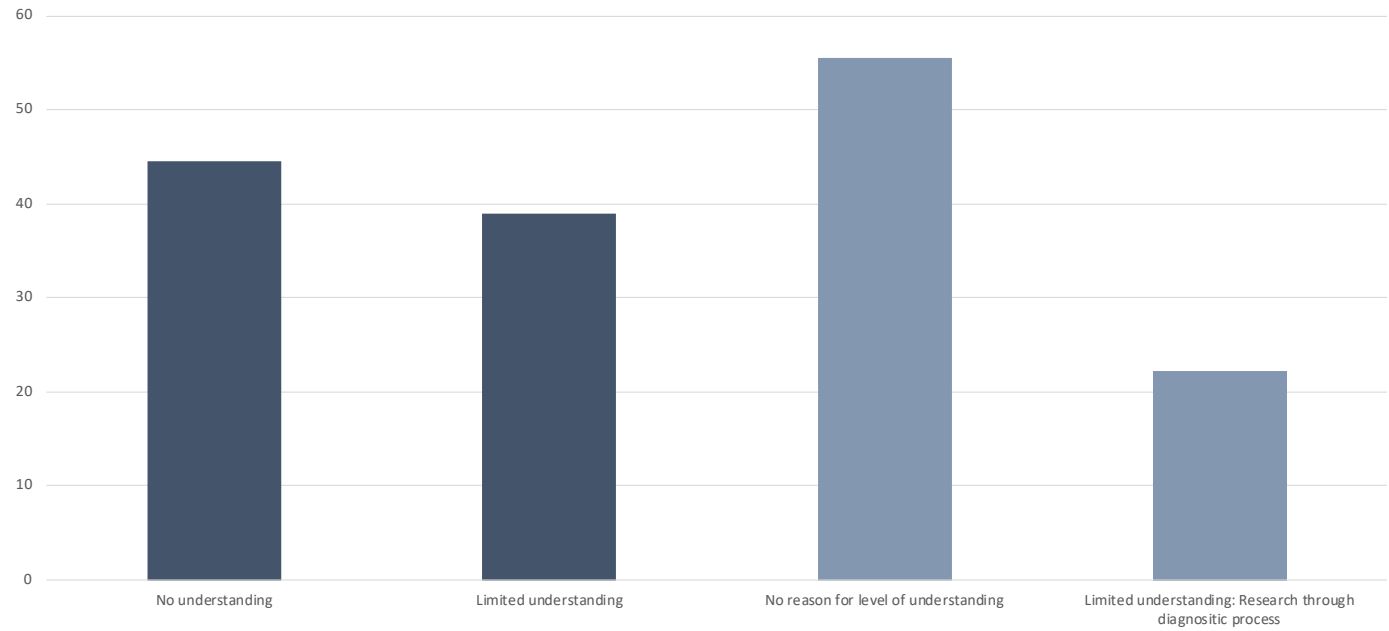

Figure 3.18 Understanding of disease at diagnosis

Emotional support at diagnosis

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

NMOSD

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

MOG

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

NMOSD or MOG

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

Table 3.23: Emotional support at diagnosis

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

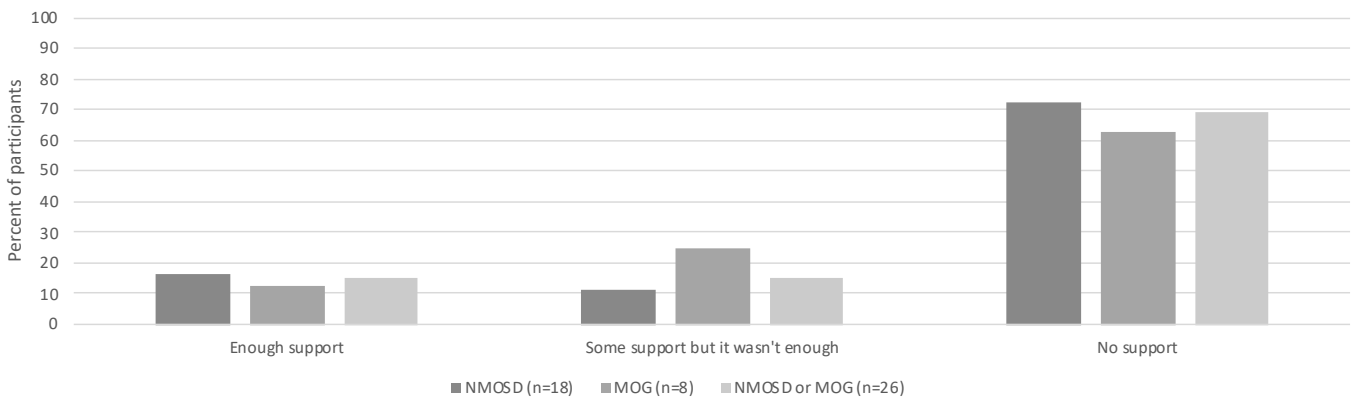

Figure 3.19: Emotional support at diagnosis

Information at diagnosis

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

NMOSD

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

MOG

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

NMOSD or MOG

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

Table 3.24: Information at diagnosis

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

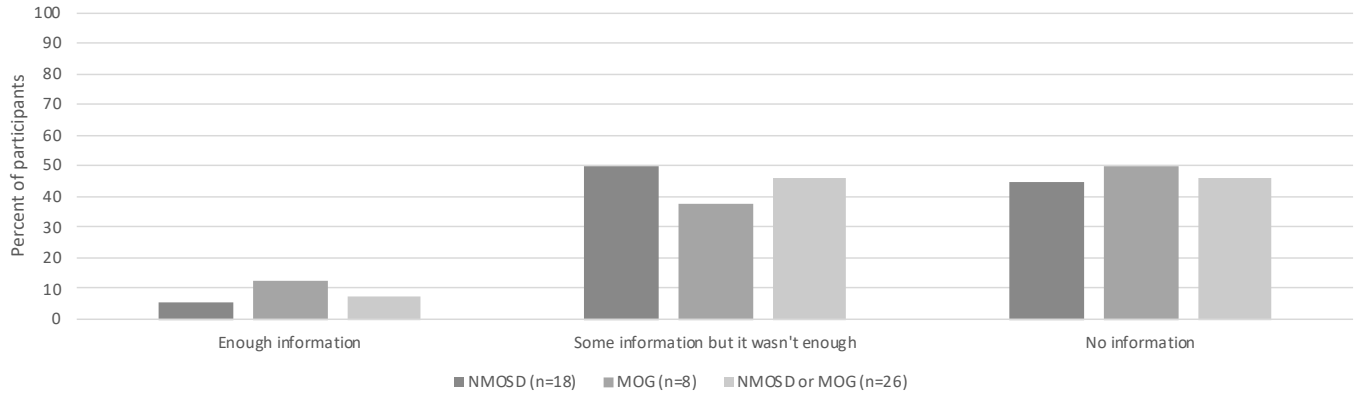

Figure 3.20: Information at diagnosis

Costs at diagnosis

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

NMOSD

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

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

MOG

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

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

NMOSD or MOG

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

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

Table 3.25: Costs at diagnosis

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

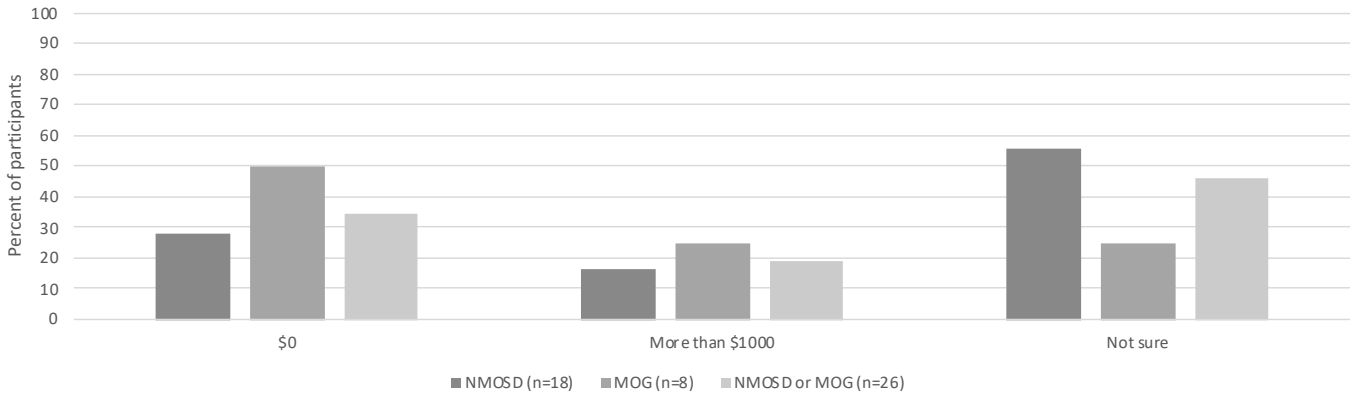

Figure 3.21: Costs at diagnosis

Table 3.26: Burden of diagnostic costs

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

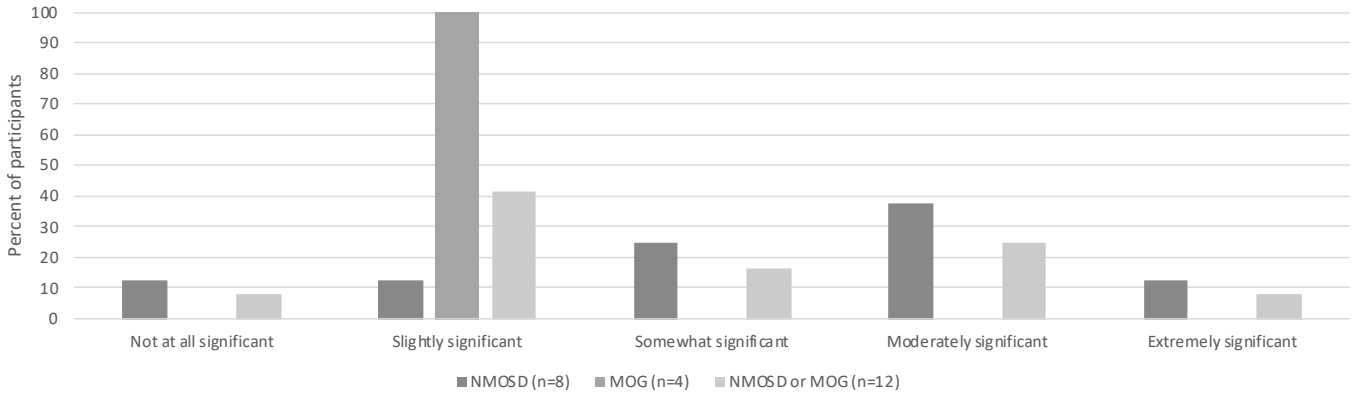

Figure 3.22: Burden of diagnostic costs

Genetic tests and biomarkers

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

NMOSD

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

MOG

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

NMOSD and MOG

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

Table 3.27: Discussions about biomarkers

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

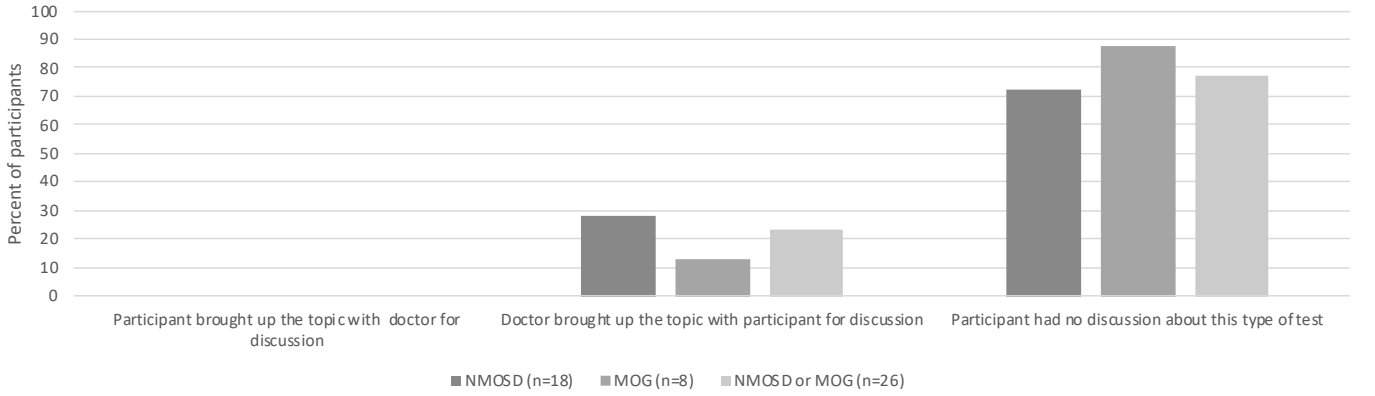

Figure 3.23: Discussions about biomarkers

Experience of genetic tests and biomarkers

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

NMOSD

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

MOG

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

NMOSD or MOG

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

Table 3.28: Experience of genetic tests and biomarkers

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

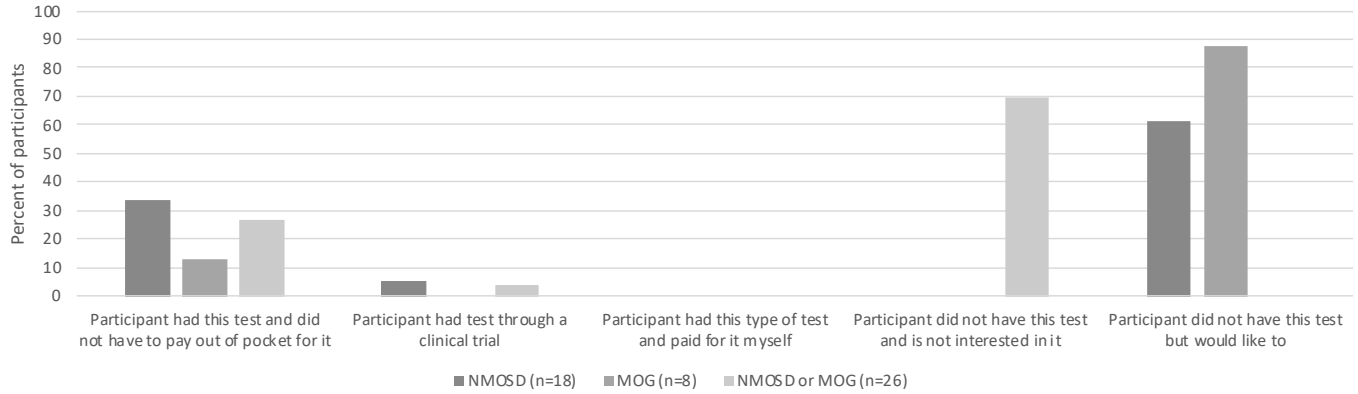

Figure 3.24: Experience of genetic tests and biomarkers

Specific biomarkers or genetic markers

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

NMOSD

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

MOG

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

NMOSD or MOG

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

Table 3.29: Specific biomarkers or genetic markers

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

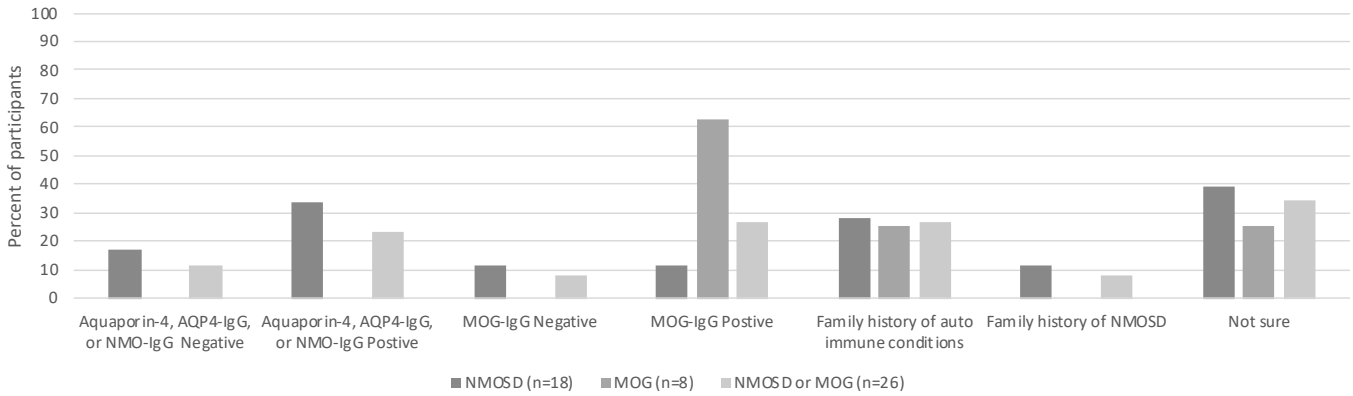

Figure 3.25: Specific biomarkers or genetic markers

Understanding of prognosis

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Table 3.30: Understanding of prognosis

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

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

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

Table 3.32: Understanding of prognosis (Subgroup variations)

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

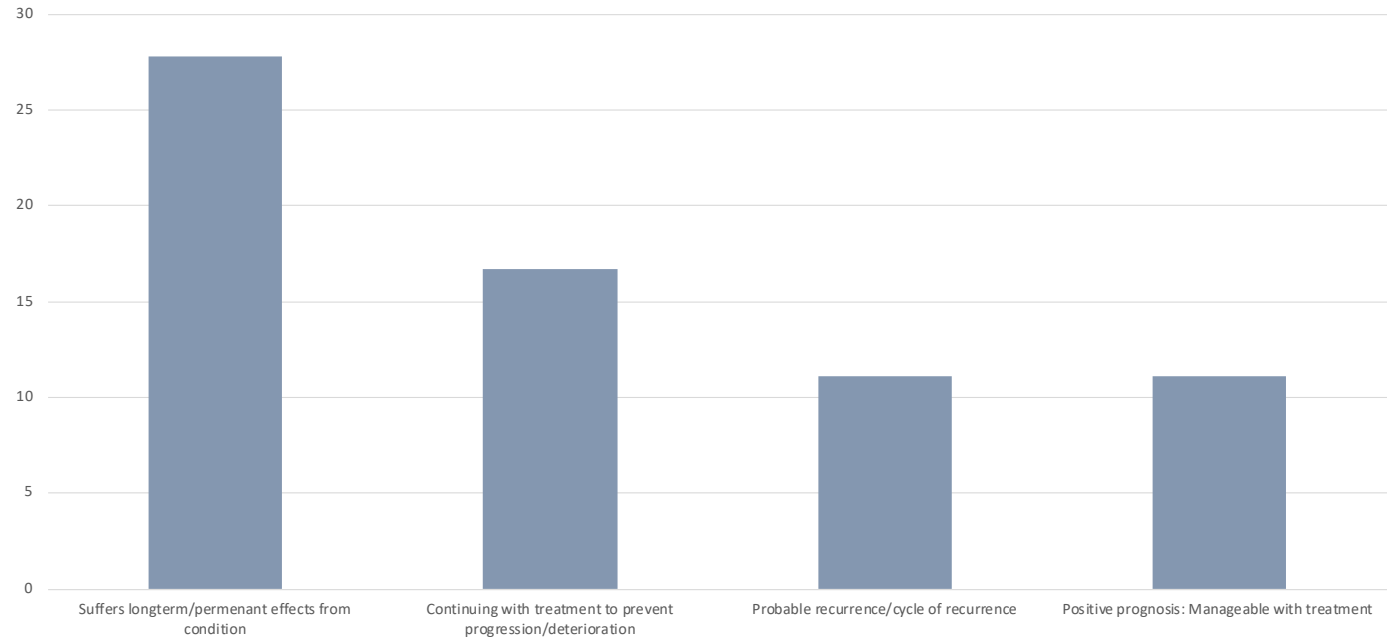

Figure 3.26: Understanding of prognosis

Section 4

Decision-making

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common was participants being presented with multiple treatment options and this was described by 11 participants (61.11%). This was followed by participants being presented with one treatment option (n=6, 33.33%).

Conversations about treatment: Participation in discussions

Of the participants who were presented with multiple options six (33.33%) described being told what to do without discussion, and four (22.22%) participated in the decision-making process.

Conversations about treatment: Specific treatments discussed

Some participants described specific treatments that were discussed, the most common was rituximab (n=11, 61.11%), followed by steroids (n=7, 38.89%), and plasma exchange (n=5, 27.78%).

Considerations when making decisions about treatment

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported consideration was side effects as part of multiple aspects that they consider when making decisions about treatment, and this was described by five participants (27.78%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 16 participants (88.89%) that felt the way they made decisions about treatment had changed over time.

Decision-making over time

Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed and/or assertive (n=6, 33.33%).

Personal goals of treatment or care

Participants were asked what their personal goals of treatment or care were. The most common response was participants wanting to maintain their condition/prevent worsening and relapse of their condition (n=7, 38.89%).

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common was participants being presented with multiple treatment options and this was described by 11 participants (61.11%). This was followed by participants being presented with one treatment option (n=6, 33.33%).

Participant describes being presented with multiple treatment options

They said to me that they would…The steroids and then the IVIG and then the plasmapheresis. That's what they've given her. Participant NMOCA_006

I was put on the first line of treatment which was Imuran or azathioprine, so tablets. That was after the first optical diagnosis. Then I was got up to the desired dose. I can't remember what it was, I think it was about 1,000 milligrams or something, and I got pancreatitis and so they thought that- and I was on the oral steroids as well, prednisolone, but they thought it was azathioprine that had caused the pancreatitis, so I was pulled off that. Participant NMO_017

They put me on a high dose of steroids again. Then they put me on CellCept which I had a reaction to and I actually got, I think they call it pseudogout. My knee puffed up and it was full of fluid and I couldn't walk. I went back to the hospital and they drained that, twice I had to do it and then that settled down, but it was making me very ill as well, so he took me off that. I've been on plasma exchanges and Rituximab and Methotrexate. Participant NMO_007

Participant describes being presented with one treatment option

It was very vague. The hospital just said that they did the methylpred for five days. There was no offer of any other-- like a plasma exchange, or anything like that. Participant NMO_009

Basically that there was none for MS-specific, sorry, for NMO specific in Australia, not on the PBS anyway. I am on Ocrevus. He recommended Ocrevus to treat it, basically. That's what we decided to go with. Participant NMO_003

Pretty much that I was told I just needed one treatment which was an infusion, and I had to wait for approval from the board of the hospital before I could have it. Once they got the approval, then they could put me in for it, and that's rituximab. Participant NMO_008

Table 4.1: Conversations about treatment

Conversations about treatment	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very goo physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes being presented with multiple treatment options	11	61.11	5	55.56	6	66.67	5	62.50	6	60.00	7	77.78	4	44.44
Participant describes being presented with one treatment option	6	33.33	3	33.33	3	33.33	3	37.50	3	30.00	1	11.11	5	55.56
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

Conversations about treatment	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes being presented with multiple treatment options	11	61.11	6	60.00	5	62.50	4	66.67	7	58.33	4	57.14	7	63.64
Participant describes being presented with one treatment option	6	33.33	4	40.00	2	25.00	2	33.33	4	33.33	3	42.86	3	27.27
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

Conversations about 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 being presented with multiple treatment options	11	61.11	7	87.50	18	69.23	9	90.00	10	62.50	1	50.00	2	66.67	9	60.00
Participant describes being presented with one treatment option	6	33.33	1	12.50	7	26.92	0	0.00	5	31.25	1	50.00	1	33.33	5	33.33
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 4.2: Conversations about treatment (Subgroup variations)

Conversations about treatment	More frequent	Less frequent
Participant describes being presented with multiple treatment options	Moderate to very poor physical function	Good to very good physical function

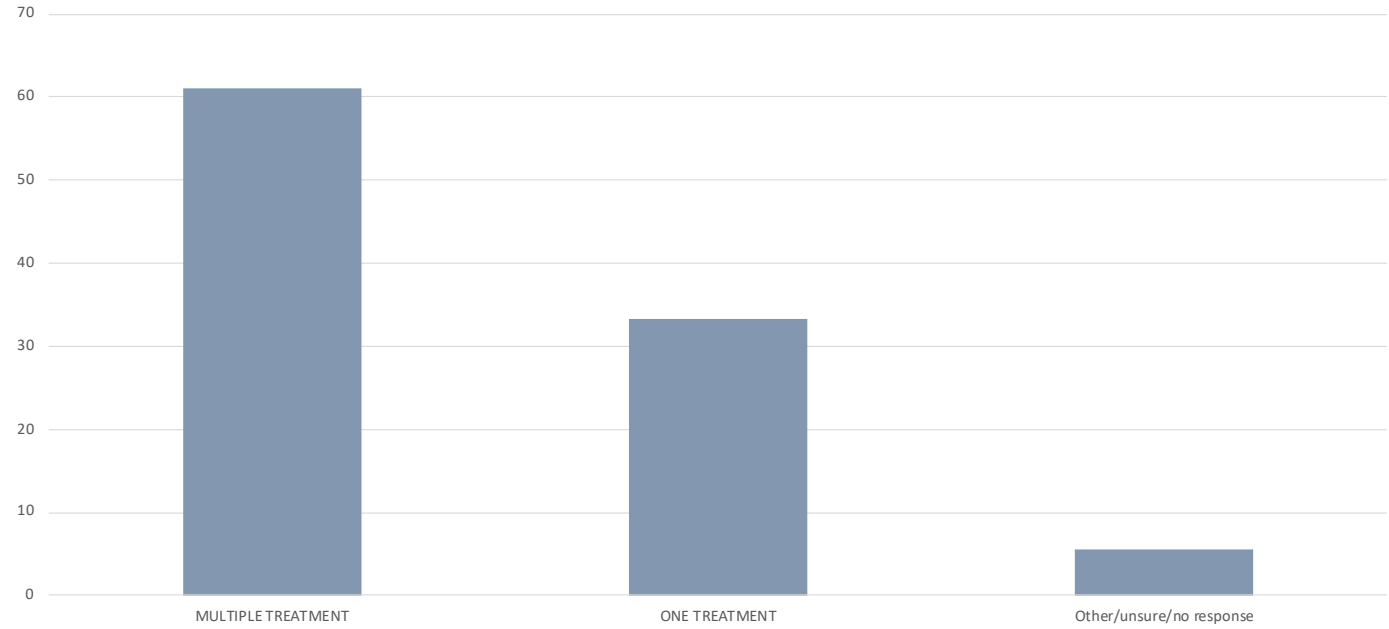

Figure 4.1: Conversations about treatment

Conversations about treatment: Participation in discussions

Of the participants who were presented with multiple options six (33.33%) described being told what to do without discussion, and four (22.22%) participated in the decision-making process.

Participant describes being presented with multiple options: They were told what to do without discussion

In the hospital, because I still don't know what was going on, I knew I was on a heavy steroid infusion. IV methyl pred. The neurologist saying that once I'm discharged from hospital, I will probably need infusions and could also need to take oral prednisolone. That was all that was given to me. I wouldn't call an option as such because I know nothing about it and she basically told me, "Yes, this is what you'll do. This is what you'll do. Participant NMO_001.

I think they're very minimal. He told me, within the first few days, that he was certain that it was neuromyelitis, that he was going to try and treat with steroids first to see if it made any change, and there'd been no difference. That's when he told me about the plasmapheresis, but I was never told about what to expect or what was happening or anything like that. I was just moved down to ICU, and next minute, I was having some lines put in my neck and just things like that. Then I had the pipe put in. It was quite confronting. I didn't know what to expect. Participant NMO_011

Participant describes being presented with multiple options: Participated in the decision-making process

They gave me an MS nurse rather than the neurologist. She rang me and I think it was Eculizumab and sent me a whole lot of paperwork about the Rituximab, the Eculizumab and wanted me to take both, because, apparently, they go hand in hand. I was a bit reluctant at first. I didn't start treatment till February, but I needed to do my research and look at what were the side effects. The MS nurse that I had, her mum had been on Rituximab for arthritis. She said, "My mum has been on it for 10 years. She's doing well, she hasn't had any side effects." That was a bit reassuring because I thought, "Well, you're allowing your mum and you're a nurse." But I did notice that it was monoclonal… Then the other one, the Eculizumab, that was chemo. I thought, "Well, I don't want to have chemo treatment because I haven't got cancer," but I knew I needed something. I said, "Look, I'll accept the Rituximab and the Rituximab only." Because the risk was too great of having a relapse and losing my sight. Participant NMO_015

There was a lot of discussion about safety and efficacy of the various medications that were available, and the three of us made an informed decision about which ones to trial. The neurologist, the professor was basically saying, "Look, it might

take a few goes to find the right one for you so, I think you should start with this one and then move on to that one and we'll just see how you go." We had lots of discussion about which ones. Participant NMO_016

Because I travel every year, I travel solo and I still visit people within NMO, I plan my journey, I'm determined to live my life really fully. Even though- because I had to walk away from teaching, I was always passionate about camping. That's why I go and do that. I've now got a partner that I can do it with, but for four years, I did go solo on short and long trips all around Australia on the Mycophenolate. He didn't want to put me on Rituximab because of the fact that I like to travel. Participant NMO_004

Table 4.3: Conversations about treatment: Participation in discussions

Conversations about treatment: Participation in discussions	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes being presented with multiple options: They were told what to do without discussion	6	33.33	2	22.22	4	44.44	4	50.00	2	20.00	3	33.33	3	33.33
Participant describes being presented with multiple options: Participated in the decision-making process	4	22.22	2	22.22	2	22.22	1	12.50	3	30.00	3	33.33	1	11.11

Conversations about treatment: Participation in discussions	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes being presented with multiple options: They were told what to do without discussion	6	33.33	3	30.00	3	37.50	2	33.33	4	33.33	2	28.57	4	36.36
Participant describes being presented with multiple options: Participated in the decision-making process	4	22.22	2	20.00	2	25.00	2	33.33	2	16.67	2	28.57	2	18.18

Conversations about treatment: Participation in discussions	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes being presented with multiple options: They were told what to do without discussion	6	33.33	3	37.50	9	34.62	4	40.00	5	31.25	1	50.00	2	66.67	4	26.67
Participant describes being presented with multiple options: Participated in the decision-making process	4	22.22	4	50.00	8	30.77	3	30.00	4	25.00	0	0.00	0	0.00	4	26.67

Table 4.4: Conversations about treatment: Participation in discussions (Subgroup variations)

Conversations about treatment: Participation in discussions	More frequent	Less frequent
Participant describes being presented with multiple options: They were told what to do without discussion	More relapses Low to moderate fear	Fewer relapses High to very high fear

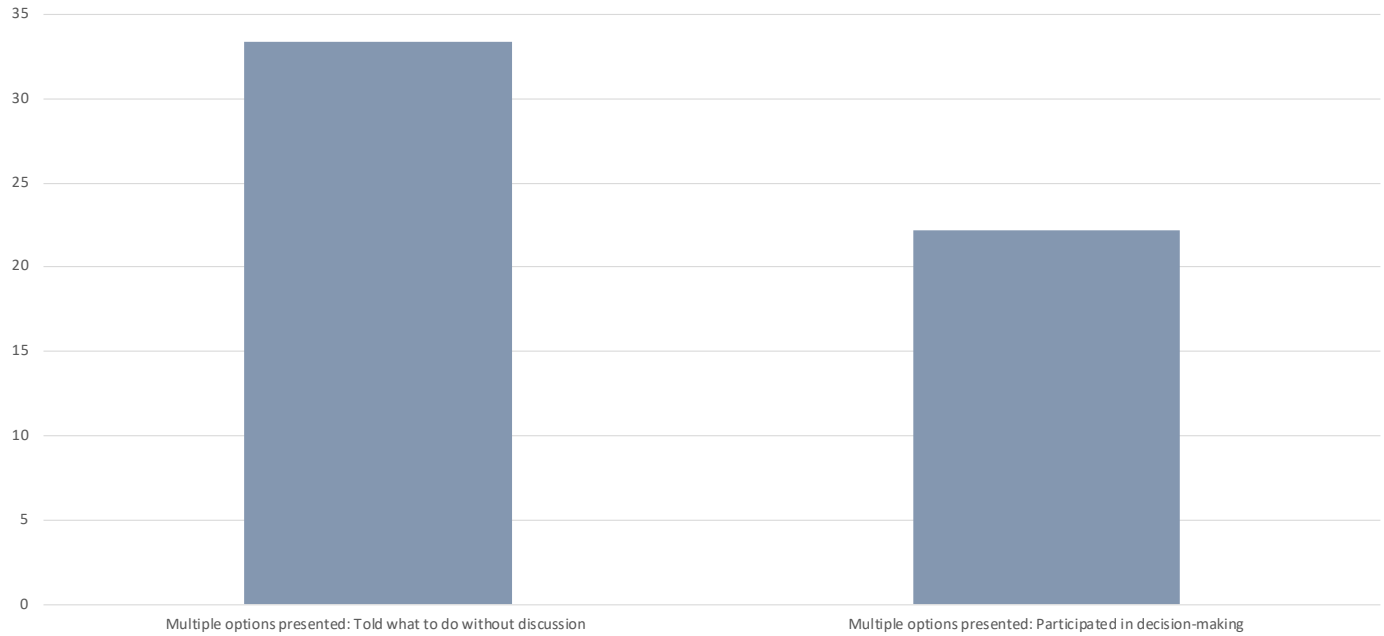

Figure 4.2: Conversations about treatment: Participation in discussions

Conversations about treatment: Specific treatments discussed

Some participants described specific treatments that were discussed, the most common was rituximab (n=11, 61.11%), followed by steroids (n=7, 38.89%), and plasma exchange (n=5, 27.78%).

Participant describes being presented with the option of rituximab

After the second I went, that's when they put me on Rituximab and really, that's the only thing apart from my vitamin D3/B12 that I have. Participant NMO_012

In 2010 I started on Rituximab. I was also on Azathioprine and Prednisone. Azathioprine I think was a half a tablet or one tablet 50mg I think, and Prednisone was dropped down to 1mg a day and then I would get a Rituximab infusion. Every time my B cells returned I'd get another infusion which was usually around 1.8 years. Participant NMO_002

They gave me an MS nurse rather than the neurologist. She rang me and I think it was Eculizumab and sent me a whole lot of paperwork about the Rituximab, the Eculizumab and wanted me to take both, because, apparently, they go hand in hand. I was a bit reluctant at first. I didn't start treatment till February, but I needed to do my research and look at what were the side effects. Participant NMO_015

Participant describes being presented with the option of steroids

Well, they basically told us that he needed to be admitted into hospital and he needed to be on high dose steroids. Participant NMOCA_007

The steroids and then when it happened again, seven months later, boom back on the IV steroids. Participant NMO_012

Yes. They, obviously, had started the steroids and the plasma exchange before diagnosing him with NMO. They believed it was an autoimmune disease they were just looking into, or they weren't certain on which one it was yet. They explained their treatment for most autoimmune diseases would be the plasma exchange and the steroids. Once they diagnosed him with the NMO they explained that Rituximab would deplete his B cells, so they started it that day. Participant NMOCA_002

Participant describes being presented with the option of plasma exchange

I've been on plasma exchanges and Rituximab and Methotrexate. Participant NMO_007

The steroids and then when it happened again, seven months later, boom back on the IV steroids. [chuckles] Then they gave me plasma exchange. Participant NMO_012

Yes. They, obviously, had started the steroids and the plasma exchange before diagnosing him with NMO. They believed it was an autoimmune disease they were just looking into, or they weren't certain on which one it was yet. They explained their treatment for most autoimmune diseases would be the plasma exchange and the steroids. Once they diagnosed him with the NMO they explained that Rituximab would deplete his B cells, so they started it that day. They have said that it's, obviously, early days for us. NAME PERSON CARED FOR is most likely to continue having Rituximab throughout his life in order to prevent relapses. Participant NMOCA_002

Table 4.5: Conversations about treatment: Specific treatment discussed

Conversations about treatment: Specific treatment discussed	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes being presented with the option of rituximab	11	61.11	5	55.56	6	66.67	5	62.50	6	60.00	4	44.44	7	77.78
Participant describes being presented with the option of steroids	7	38.89	4	44.44	3	33.33	4	50.00	3	30.00	4	44.44	3	33.33
Participant describes being presented with the option of plasma exchange	5	27.78	1	11.11	4	44.44	1	12.50	4	40.00	4	44.44	1	11.11

Conversations about treatment: Specific treatment discussed	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes being presented with the option of rituximab	11	61.11	6	60.00	5	62.50	3	50.00	8	66.67	3	42.86	8	72.73
Participant describes being presented with the option of steroids	7	38.89	4	40.00	3	37.50	2	33.33	5	41.67	2	28.57	5	45.45
Participant describes being presented with the option of plasma exchange	5	27.78	5	50.00	0	0.00	2	33.33	3	25.00	1	14.29	4	36.36

Conversations about treatment: Specific treatment discussed	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes being presented with the option of rituximab	11	61.11	3	37.50	14	53.85	2	20.00	10	62.50	1	50.00	1	33.33	10	66.67
Participant describes being presented with the option of steroids	7	38.89	4	50.00	11	42.31	7	70.00	7	43.75	0	0.00	2	66.67	5	33.33
Participant describes being presented with the option of plasma exchange	5	27.78	1	12.50	6	23.08	3	30.00	4	25.00	1	50.00	2	66.67	3	20.00

Table 4.6: Conversations about treatment: Specific treatment discussed

Conversations about treatment: Specific treatment discussed	More frequent	Less frequent
Participant describes being presented with the option of rituximab	Good to very good physical function Aged 45 or older	Moderate to very poor physical function Mid to low socioeconomic status Aged 18 to 44
Participant describes being presented with the option of steroids	Low to moderate fear	Aged 18 to 44
Participant describes being presented with the option of plasma exchange	More relapses High to very high fear Moderate to very poor physical function Trade or high school	Low to moderate fear Good to very good physical function University Aged 18 to 44

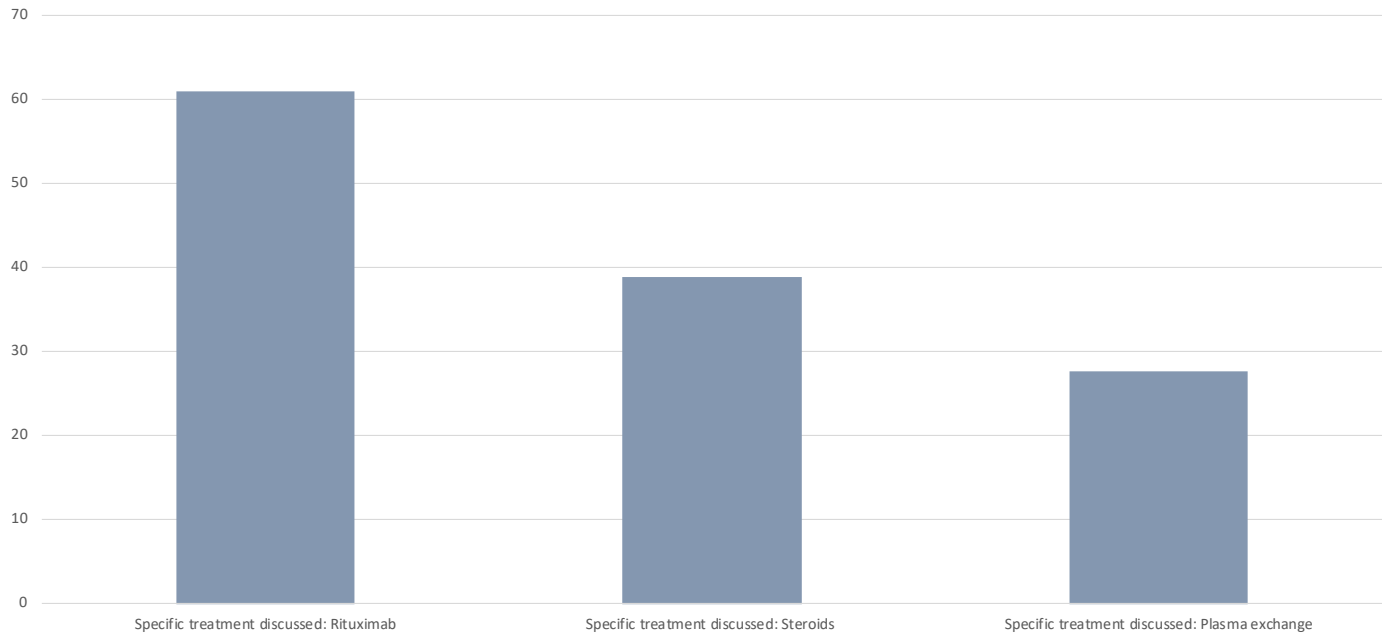

Figure 4.3: Conversations about treatment: Specific treatment discussed

Considerations when making decisions about treatment

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported consideration was side effects as part of multiple aspects that they consider when making decisions about treatment, and this was described by five participants (27.78%).

Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment

I look at side effects and how they all affect me. Like how often I need to take something, for example. I just want to live my life the most normal as I can. I don't want to be taking pills three times a day. Participant NMO_005

I look at the side effects of treatment. I look at research, I look at, obviously, other people on Facebook and what they've had. Participant NMO_015

The side effects, how effective the medication, and then the side effect of the medication. Participant NMO_001

Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment

I think really the main thing is the effectiveness of it and whether or not that person understands your condition and is supportive of you. Participant NMO_004

The side effects, how effective the medication, and then the side effect of the medication. Participant NMO_001

Probably long term, and it is working at the moment, knowing that it is holding. If I didn't have my Rituximab, or if I get sick with the NMO, it strikes quite fast. Virtually what is probably in the mind. I know that the Rituximab that I'm having or plasma is a way of helping me type thing. Participant NMO_013

Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment

Oh, cost. Cost would be one of the things, that's because I no longer work. Participant NMO_011

Oh, cost is definitely a huge part of it. If the PBS didn't exist I would not be getting treatment. Participant NMO_014

Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment

I put all my trust in NAME DOCTOR because so far he's kept me going. He's got me out of trouble a few times, like when I've had an attack and I'm on my way to the hospital, when I get there he's waiting there for me. Participant NMO_007

Pretty much I was told I didn't have a decision to make because that was my only option. I did look into it and it seems to be the most popular one that people use for NMO, so I was quite comfortable with that. Participant NMO_008

I don't think I really make the decisions, I rely on my neurologist to make the decisions. Participant NMO_006

Participant describes taking the long-term impact and side effects of treatment into account as part of multiple aspects that they consider when making decisions about treatment

How it affects him. That is the main thing. In the long term and also in the short term and whether it affects his everyday ability to do his work because he is still obviously working. That's probably the main concern but it doesn't affect him adversely. Participant NMOCA_003

When I say side effects, I mean long-term issues, whether anything long-term would impact on his health. My work situation, because he's dependent on me. I have to try and juggle things around my work situation to get him to treatment. I guess that's really it. Participant NMOCA_007

Side effects, strictly long-term side effects. I understand that I'm to be immunosuppressed but what it's opening me up to. Participant NMO_014

Participant describes weighing up the benefits versus the risks as part of multiple considerations

I look at the side effects of treatment. I look at research, I look at, obviously, other people on Facebook and what they've had. I guess I gauge it on me because I know myself better than anyone and I look at what's going to be beneficial for my well-being. Participant NMO_015

Table 4.7 Considerations when making decisions about treatment

Considerations when making decisions about treatment	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	5	27.78	3	33.33	2	22.22	4	50.00	1	10.00	2	22.22	3	33.33
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	4	22.22	3	33.33	1	11.11	2	25.00	2	20.00	3	33.33	1	11.11
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	4	22.22	2	22.22	2	22.22	3	37.50	1	10.00	2	22.22	2	22.22
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	3	16.67	0	0.00	3	33.33	0	0.00	3	30.00	2	22.22	1	11.11
Participant describes taking the long term impact and side effects of treatment into account as part of multiple aspects that they consider when making decisions about treatment	2	11.11	2	22.22	0	0.00	1	12.50	1	10.00	1	11.11	1	11.11
Participant describes weighing up the benefits versus the risks as part of multiple considerations	2	11.11	2	22.22	0	0.00	1	12.50	1	10.00	0	0.00	2	22.22

Considerations when making decisions about treatment	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	5	27.78	1	10.00	4	50.00	2	33.33	3	25.00	2	28.57	3	27.27
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	4	22.22	2	20.00	2	25.00	1	16.67	3	25.00	1	14.29	3	27.27
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	4	22.22	3	30.00	1	12.50	3	50.00	1	8.33	1	14.29	3	27.27
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	3	16.67	3	30.00	0	0.00	0	0.00	3	25.00	1	14.29	2	18.18
Participant describes taking the long term impact and side effects of treatment into account as part of multiple aspects that they consider when making decisions about treatment	2	11.11	2	20.00	0	0.00	1	16.67	1	8.33	0	0.00	2	18.18
Participant describes weighing up the benefits versus the risks as part of multiple considerations	2	11.11	1	10.00	1	12.50	2	33.33	0	0.00	0	0.00	2	18.18

Considerations when making decisions about 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 taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	5	27.78	6	75.00	11	42.31	3	30.00	5	31.25	0	0.00	1	33.33	4	26.67
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	4	22.22	3	37.50	7	26.92	3	30.00	4	25.00	0	0.00	1	33.33	3	20.00
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	4	22.22	2	25.00	6	23.08	0	0.00	4	25.00	0	0.00	1	33.33	3	20.00
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	3	16.67	1	12.50	4	15.38	1	10.00	2	12.50	1	50.00	0	0.00	3	20.00
Participant describes taking the long term impact and side effects of treatment into account as part of multiple aspects that they consider when making decisions about treatment	2	11.11	1	12.50	3	11.54	3	30.00	2	12.50	0	0.00	0	0.00	2	13.33
Participant describes weighing up the benefits versus the risks as part of multiple considerations	2	11.11	3	37.50	5	19.23	1	10.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 4.8: Considerations when making decisions about treatment (Subgroup variations)

Considerations when making decisions about treatment	More frequent	Less frequent
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	Low to moderate fear University	High to very high fear Trade or high school

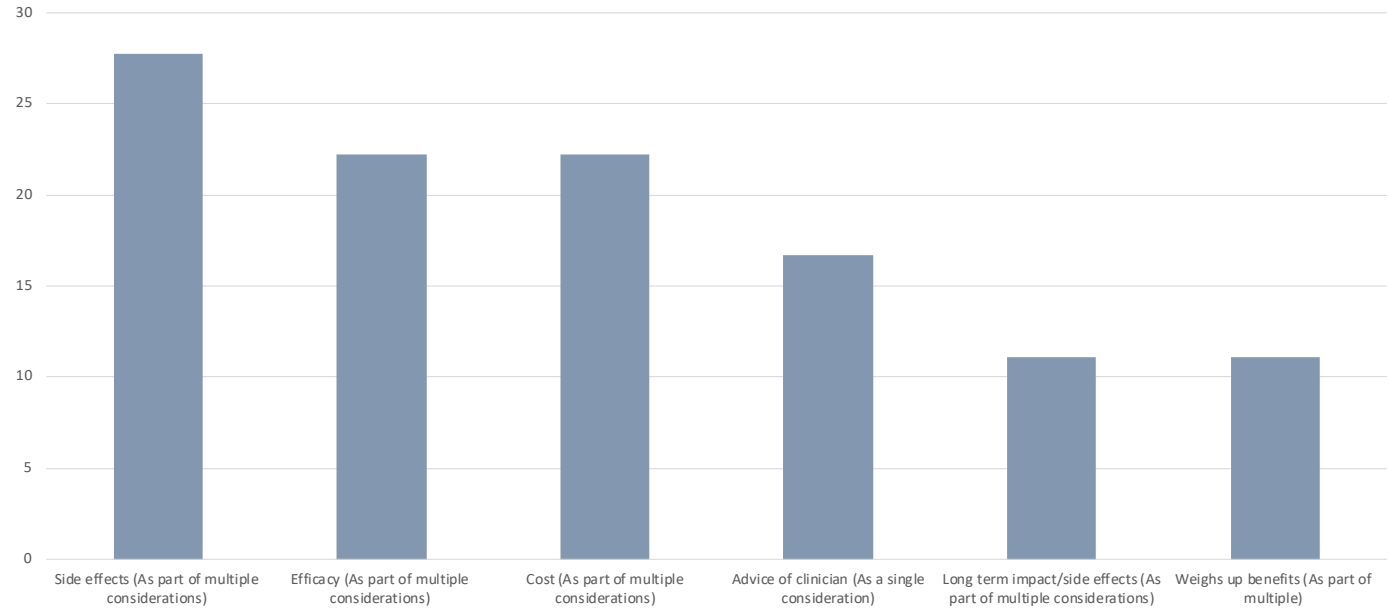

Figure 4.4 Considerations when making decisions about treatment

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 16 participants (88.89%) that felt the way they made decisions about treatment had changed over time.

Participant describes decision-making changing over time (total)

It's changed as I've learned a lot. When it first happens, you get a bit overwhelmed by it all, but I've had to teach myself, learn a lot in the nine years. If you don't learn a lot, you don't know what's happening. Participant NMO_013

No, definitely it has changed. I recently did a deep dive into what NMO is this year. Just previously I feel like you've got to be asking lots of questions and you can't with just your 10-minute session with your specialists. Participant NMO_002

No. Definitely changed after. Now, I'm researching a lot about a massive decision. I'm not just like, "Yes. Let's decide" I'm more researching and asking for advice, so I've definitely changed the way…No, definitely changed. Participant NMO_005

Participant describes no change in decision-making over time (total)

Same way. I think we are quite too early in this journey to have made any other decisions in this. I think if we went 10 years down the track, I think we probably would have changed but now it's just 18 months. Participant NMOCA_003

In the same way. Participant NMOCA_002

The same way. Participant NMO_015

Table 4.9: Decision-making over time

Decision-making over time	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes decision-making changing over time (total)	16	88.89	7	77.78	9	100.00	8	100.00	8	80.00	8	88.89	8	88.89
Participant describes no change in decision-making over time (total)	1	5.56	1	11.11	0	0.00	0	0.00	1	10.00	0	0.00	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

Decision-making over time	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes decision-making changing over time (total)	16	88.89	10	100.00	6	75.00	5	83.33	11	91.67	7	100.00	9	81.82
Participant describes no change in decision-making over time (total)	1	5.56	0	0.00	1	12.50	1	16.67	0	0.00	0	0.00	1	9.09
Other/unsure/no response	1	5.56	0	0.00	1	12.50	0	0.00	1	8.33	0	0.00	0	0.00

Decision-making over time	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 decision-making changing over time (total)	16	88.89	4	50.00	20	76.92	4	40.00	14	87.50	2	100.00	3	100.00	13	86.67
Participant describes no change in decision-making over time (total)	1	5.56	4	50.00	5	19.23	5	50.00	1	6.25	0	0.00	0	0.00	1	6.67
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 4.10: Decision-making over time (Subgroup variations)

Decision-making over time	More frequent	Less frequent
Participant describes decision-making changing over time (total)	More relapses Low to moderate fear Trade or high school Aged 18 to 44	Fewer relapses University

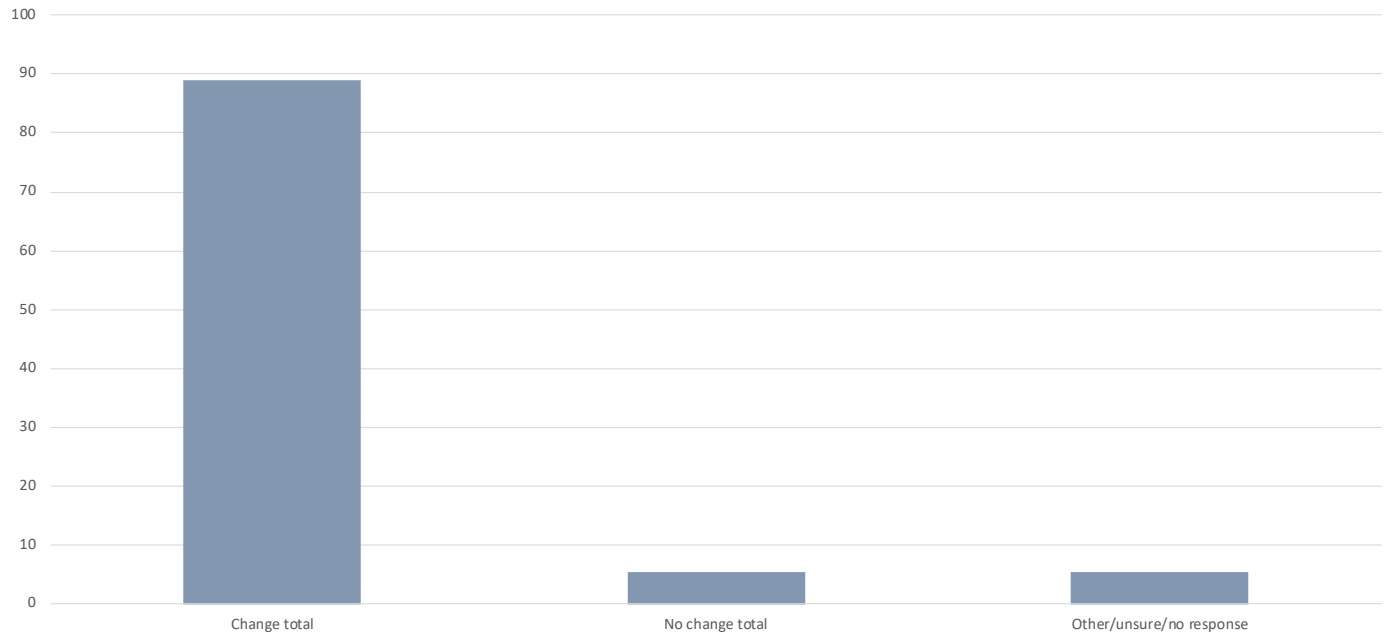

Figure 4.5: Decision-making over time

Decision-making over time

Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed and/or assertive (n=6, 33.33%).

Participant describes decision-making changing over time as they are more informed and/or more assertive

I don't trust doctors as much as I did at the start. I trust my own research more now, definitely. Participant NMO_005

No, definitely it has changed. I recently did a deep dive into what NMO is this year. Just previously I feel like you've got to be asking lots of questions and you can't with just your 10-minute session with your specialists and to see whatever they say. You got to ask questions. You've got to look into things

like diet and exercise because you know all that stuff. I don't whether it's just seen as heeby jeeby stuff that specialists don't touch. They don't touch it. They touch diet. I think there's a lot out there that could be explored especially with inflammatory diseases and things like that. Participant NMO_002

It's changed as I've learned a lot. When it first happens, you get a bit overwhelmed by it all, but I've had to teach myself, learn a lot in the nine years. Participant NMO_013

Participant describes decision-making changing over time as they are more aware of their health, responsibilities and/or limitations

My decision making has changed definitely. I always have multiple plans and ways out of things. Participant NMO_014

Yes, I've changed a lot in the way of what am I going to be able to do body-wise? Just day-to-day things. Participant NMO_012

I think we have changed the way we make decisions. This disease is really very much in your face, so that governs how you view things now, to the point where you're concerned about any relapses and so that has changed our lifestyle, I suppose. We're still fairly active but you're aware of this. Participant NMOCA_004

Participant describes no change in decision-making over time and there is no particular reason noted

Same way. I think we are quite too early in this journey to have made any other decisions in this. Participant NMOCA_003
The same way. Participant NMO_015

In the same way. Participant NMOCA_002

Table 4.11: Decision-making over time: Rationale for change

Rationale for change over time	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes decision-making changing over time as they are more informed and/or more assertive	6	33.33	3	33.33	3	33.33	4	50.00	2	20.00	3	33.33	3	33.33
Participant describes decision-making changing over time as they are more aware of their health, responsibilities and/or limitations	3	16.67	2	22.22	1	11.11	1	12.50	2	20.00	1	11.11	2	22.22

Rationale for change over time	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes decision-making changing over time as they are more informed and/or more assertive	6	33.33	2	20.00	4	50.00	0	0.00	6	50.00	4	57.14	2	18.18
Participant describes decision-making changing over time as they are more aware of their health, responsibilities and/or limitations	3	16.67	3	30.00	0	0.00	3	50.00	0	0.00	0	0.00	3	27.27

Rationale for change over time	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 decision-making changing over time as they are more informed and/or more assertive	6	33.33	3	37.50	9	34.62	1	10.00	6	37.50	0	0.00	0	0.00	6	40.00
Participant describes decision-making changing over time as they are more aware of their health, responsibilities and/or limitations	3	16.67	1	12.50	4	15.38	2	20.00	2	12.50	1	50.00	2	66.67	1	6.67

Table 4.12: Decision-making over time: Rationale for change

Rationale for change over time	More frequent	Less frequent
Participant describes decision-making changing over time as they are more informed and/or more assertive	Low to moderate fear University Higher socioeconomic status Aged 18 to 44	High to very high fear Trade or high school Mid to low socioeconomic status Aged 45 or older

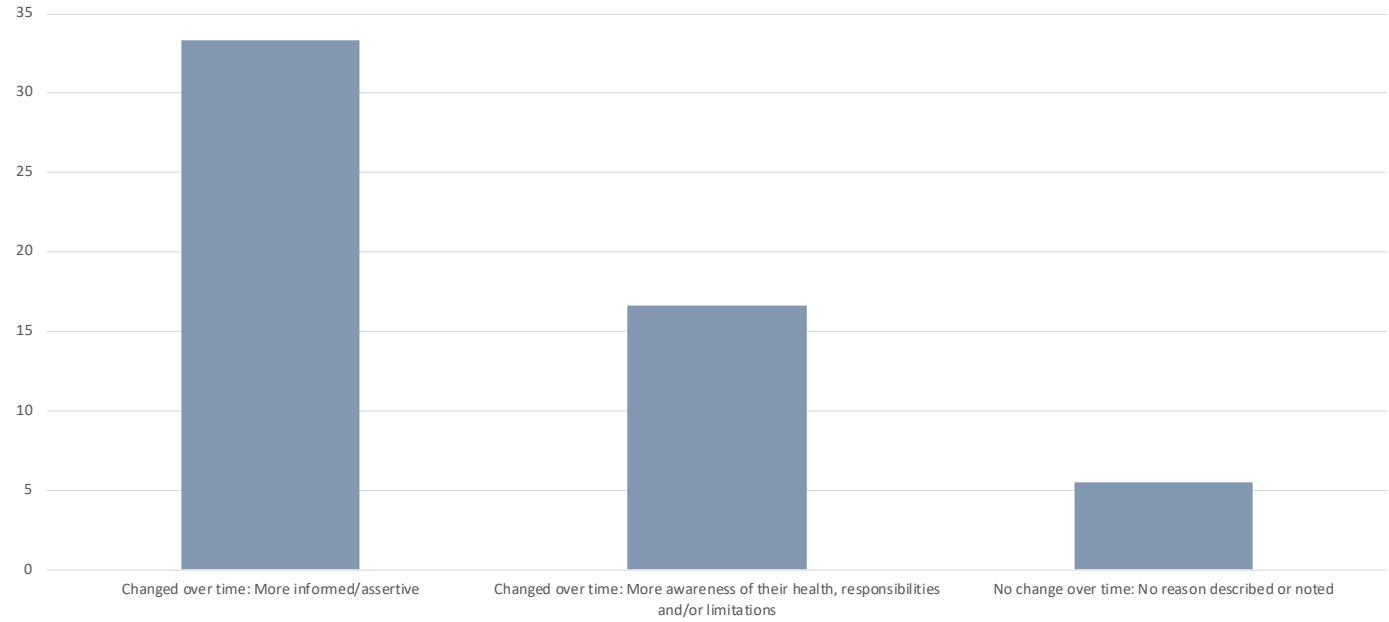

Figure 4.6: Decision-making over time: Rational for change and no change

Personal goals of treatment or care

Participants were asked what their personal goals of treatment or care were. The most common response was participants wanting to maintain their condition/prevent worsening and relapse of their condition (n=7, 38.89%).

Participant describes wanting to maintain their condition/prevent worsening and relapse of their condition

I think he just knows I don't ever want to be in a wheelchair. I don't ever want to be incontinent and I just don't want to be affected by it, which is a bit unrealistic, but that's my goal. Participant NMO_003

Well, just as long as my treatment keeps working, that is the main goal to try to keep my life as good as it can be at this moment in time, which I don't feel like it's a life at all. [chuckles] I'm still battling with life in general. Participant NMO_012

What is difficult sometimes for me to understand, and is very frightening, is that I could never tell if I was just having a flare or I was having a relapse. I have had a relapse and I've had many flares, and because it's so hot up here, if I'm outside for too long, my vision starts to disappear, so I've got a lot of aids that help me. I've got a talking microwave. Participant NMO_011

Participants describe wanting to see physical improvements in their condition

The Valium does help relax my muscles at home and I go to physio once a week, but it's a very hard effort, it's getting worse type thing because my body's starting to, as I'm getting older, every other thing is virtually going type of thing. Participant NMO_013

Yes, I have. My neurologist and the physio collaborate together about what my treatment with him is. The physio has been the most help I've had out of anyone. When I was first diagnosed I was seeing him twice a week. We got to a stage where I was, apart from the pain, actually walking unaided. Still a bit wobbly, but it was working fine. Then after the relapse I went back with about 75%. Participant NMO_009

I was walking from - my husband dropped me off at the front door, to our ward. I work in a major hospital. That was enough to put me in a like I had to sit down. I was very focused on getting to a somewhat return of less disability. Being able to walk again. That was my main goal was I didn't want to be in a wheelchair. Participant NMO_017

Participant describes wanting to live independently

Yes. Absolutely. Well, NAME PERSON CARED FOR's whole goal is to get medical stability so that she can actually have a life. She's 23 now, she got sick at 13, and she literally hasn't had any social interaction,

any schooling education, nothing. She's just been literally sick. In and out of hospital, in and out of doctors' offices and therapy. The big goal is to find stability, is to be able to have a life. Participant NMO_016

I guess so. For me, it's more about now-- Because I've been quite stable the last six months, for me, it's been more about getting back my-- Because I'm very dependent now on people around me, I had to move back home, I don't drive. I stopped working, and I was in my last year of university, my second degree. Personally, everything now is about just getting my independence, like not being so dependent on others. I think because of this coronavirus situation in LOCATION METROPOLITAN now, we haven't really discussed anything for the last six months since I've been disabled. Participant NMO_005

The only goals that I have is that I'm registered through NDIS, so my goals are to be able to continue to live independently, and so I have support workers come in to help me. Participant NMO_011

Participant describes no personal goals of treatment or care (general)

No. Participant NMOCA_007

Not exactly. No. Participant NMO_008

No. Participant NMO_014

Participant describes wanting to reduce or not have medication

I don't like the side effects, long-term of mycophenolate with the increased chance of skin cancers and lymphoma. I think they're my concerns about being on it long term. I always have this fight with myself, internal dialogue going on. I also talk about it with my MS specialist, I have a fantastic relationship with him. He was invited to my conference as well. Every time I see him, I go, "I wish I could go off them." Participant NMO_004

Yes. I told them that I don't want anything anymore that's going to give me horrible side effects and they've been really good with that. I no longer take rituximab after pulling a nail and tooth thing. I can't do it. It's giving me a flare. I had very severe side effects from rituximab. They changed me to IVIG. That's a goal. That's to be on treatment and not really go through that many side effects, but at the end of the day, my actual goal is not to be on treatment anymore. Participant MOG_006

I started on a new drug that has a protocol that you have to have the infusion every six months. I really would like to move to only when my B cells return again like I was doing on the other drugs. Just lessened drug intake as much as I can. That would do. Participant NMO_002

Table 4.13: Personal goals of treatment or care

Personal goals of treatment or care	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes wanting to maintain their condition/prevent worsening and relapse of their condition	7	38.89	2	22.22	5	55.56	2	25.00	5	50.00	5	55.56	2	22.22
Participants describe wanting to see physical improvements in their condition	3	16.67	3	33.33	0	0.00	1	12.50	2	20.00	2	22.22	1	11.11
Participant describes wanting to live independently	3	16.67	0	0.00	3	33.33	2	25.00	1	10.00	2	22.22	1	11.11
Participant describes no personal goals of treatment or care (general)	3	16.67	2	22.22	1	11.11	1	12.50	2	20.00	0	0.00	3	33.33
Participant describes wanting to reduce or not have medication	2	11.11	1	11.11	1	11.11	2	25.00	0	0.00	1	11.11	1	11.11

Personal goals of treatment or care	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes wanting to maintain their condition/prevent worsening and relapse of their condition	7	38.89	6	60.00	1	12.50	2	33.33	5	41.67	2	28.57	5	45.45
Participants describe wanting to see physical improvements in their condition	3	16.67	2	20.00	1	12.50	1	16.67	2	16.67	0	0.00	3	27.27
Participant describes wanting to live independently	3	16.67	2	20.00	1	12.50	2	33.33	1	8.33	2	28.57	1	9.09
Participant describes no personal goals of treatment or care (general)	3	16.67	2	20.00	1	12.50	2	33.33	1	8.33	0	0.00	3	27.27
Participant describes wanting to reduce or not have medication	2	11.11	0	0.00	2	25.00	0	0.00	2	16.67	1	14.29	1	9.09

Personal goals of treatment or care	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 wanting to maintain their condition/prevent worsening and relapse of their condition	7	38.89	1	12.50	8	30.77	2	20.00	6	37.50	1	50.00	2	66.67	5	33.33
Participants describe wanting to see physical improvements in their condition	3	16.67	2	25.00	5	19.23	2	20.00	2	12.50	1	50.00	1	33.33	2	13.33
Participant describes wanting to live independently	3	16.67	2	25.00	5	19.23	0	0.00	3	18.75	0	0.00	1	33.33	2	13.33
Participant describes no personal goals of treatment or care (general)	3	16.67	1	12.50	4	15.38	1	10.00	3	18.75	0	0.00	0	0.00	3	20.00
Participant describes wanting to reduce or not have medication	2	11.11	2	25.00	4	15.38	1	10.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 4.14: Personal goals of treatment or care (Subgroup variations)

Personal goals of treatment or care	More frequent	Less frequent
Participant describes wanting to maintain their condition/prevent worsening and relapse of their condition	More relapses High to very high fear Moderate to very poor physical function Trade or high school Aged 45 or older	Fewer relapses Low to moderate fear Good to very good physical function University Aged 18 to 44

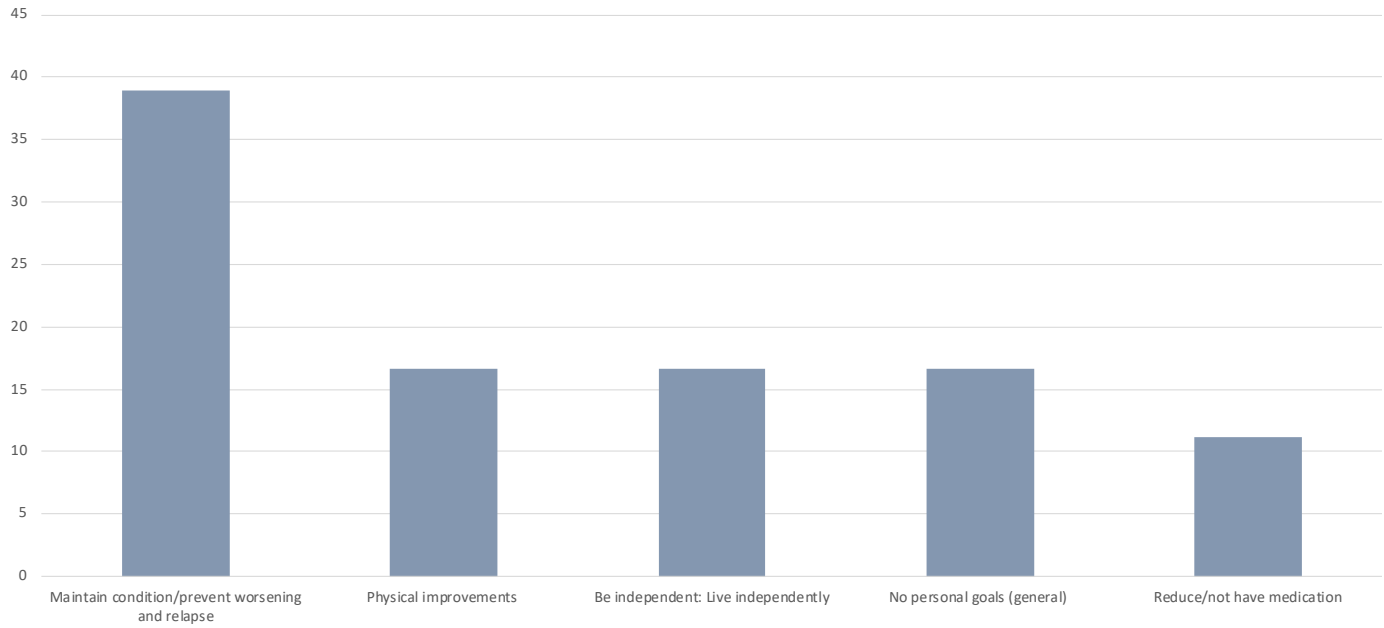

Figure 4.7: Personal goals of treatment or care

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 cancer 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 bought 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 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.

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.

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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

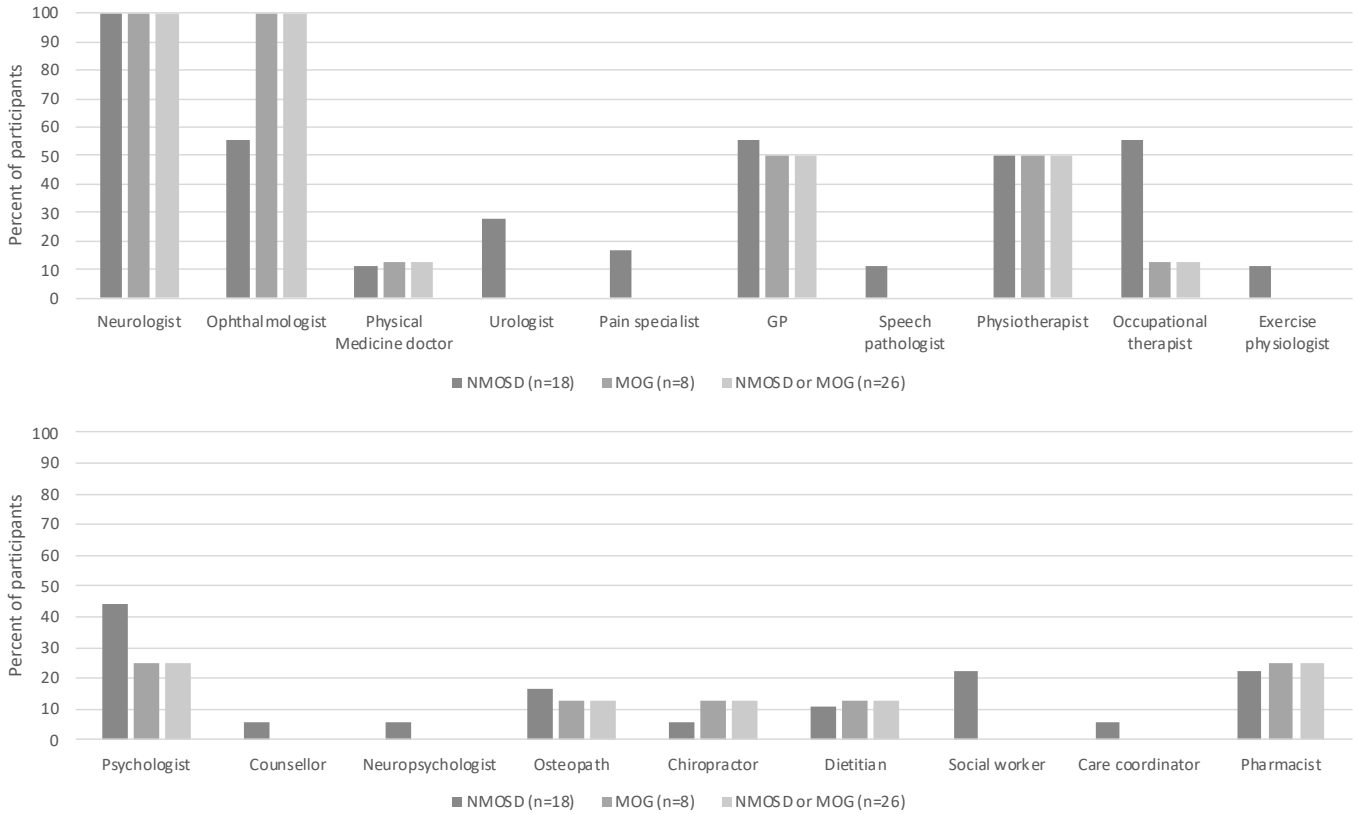

Figure 5.1: Access to healthcare professionals

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

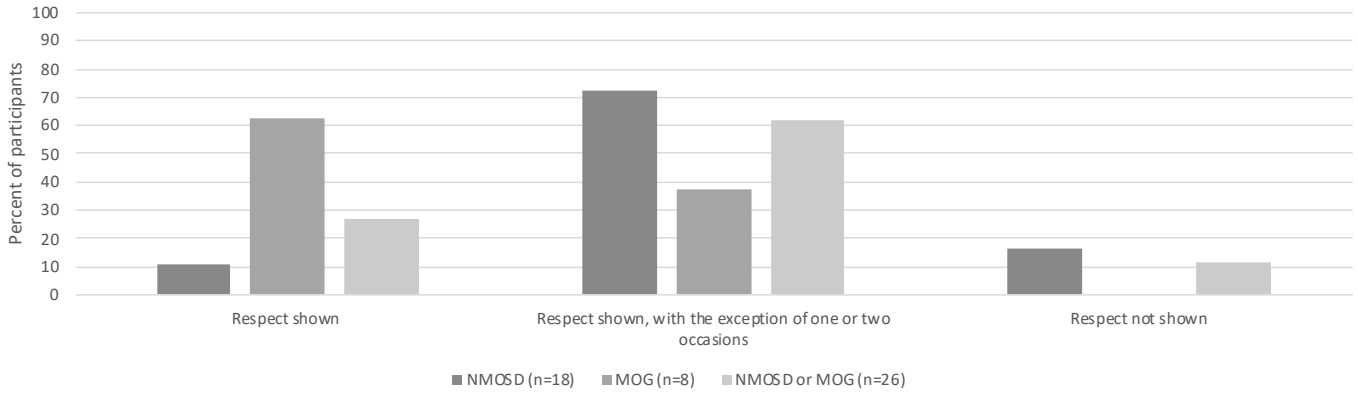

Figure 5.2: Respect shown

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

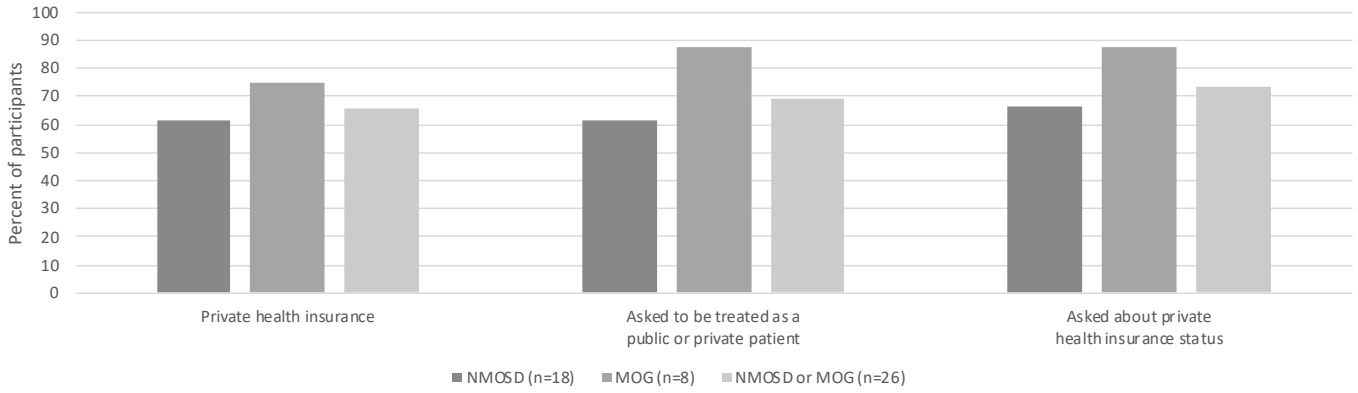

Figure 5.3: Private health insurance

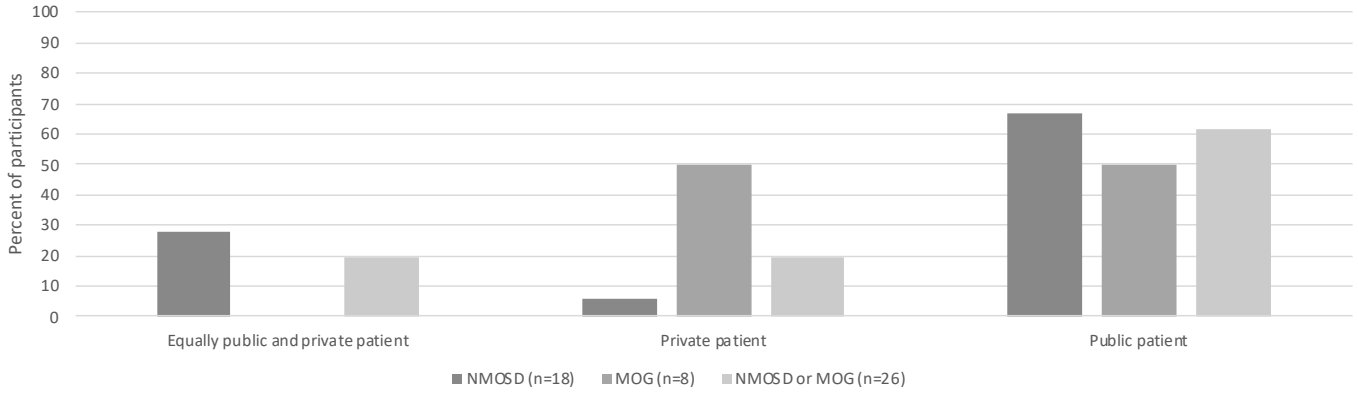

Figure 5.4: Public/private patient

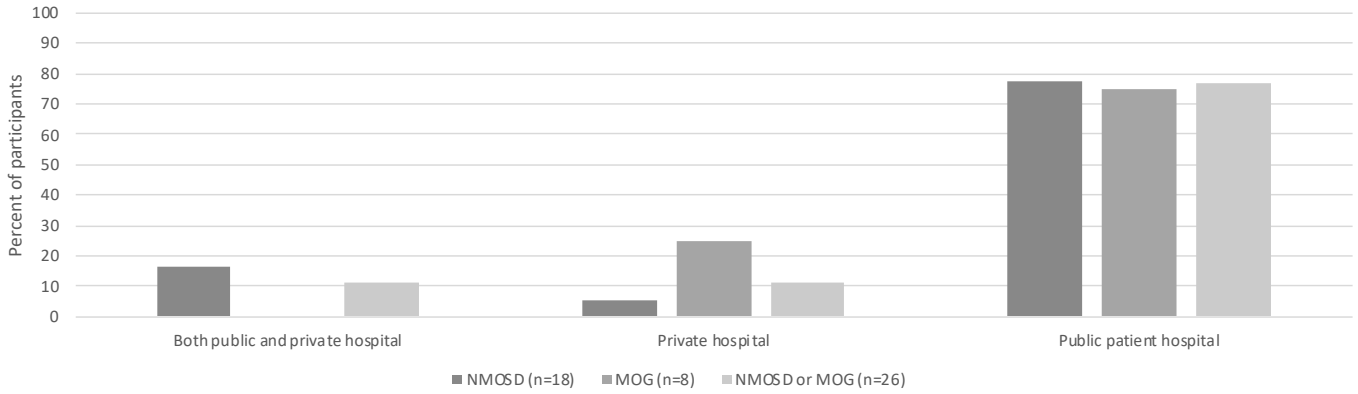

Figure 5.5: Public/private health system

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 cancer 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

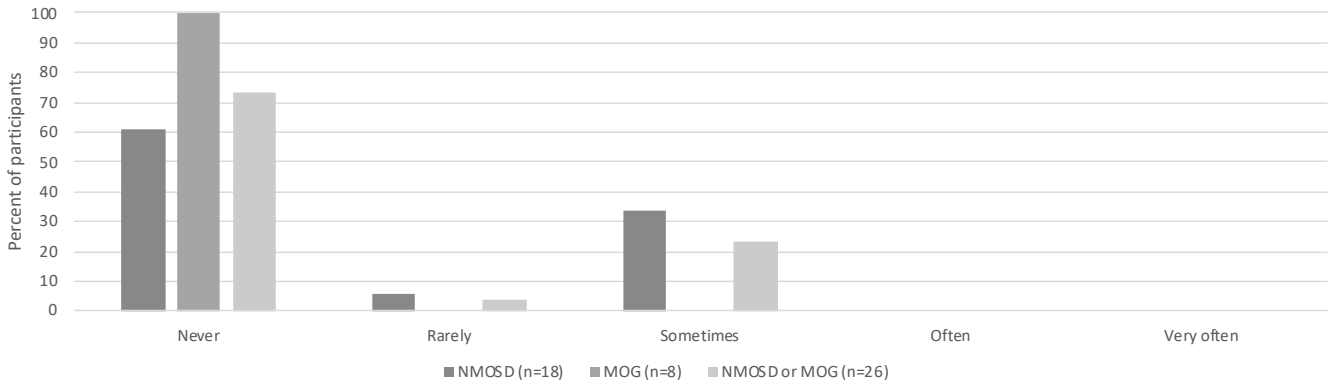

Figure 5.6: Healthcare appointments

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).

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.

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.

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

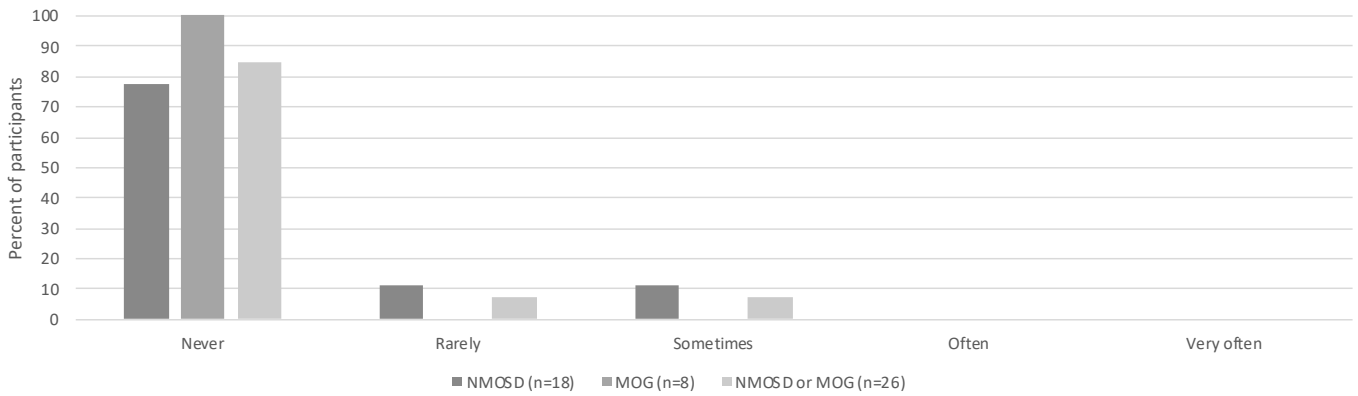

Figure 5.7: Filling prescriptions

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

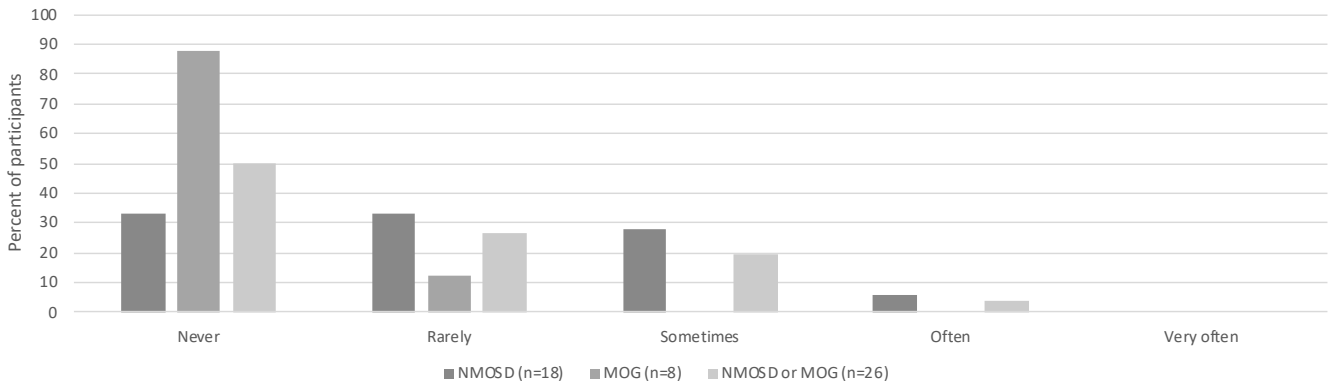

Figure 5.8: Paying for basic essentials

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

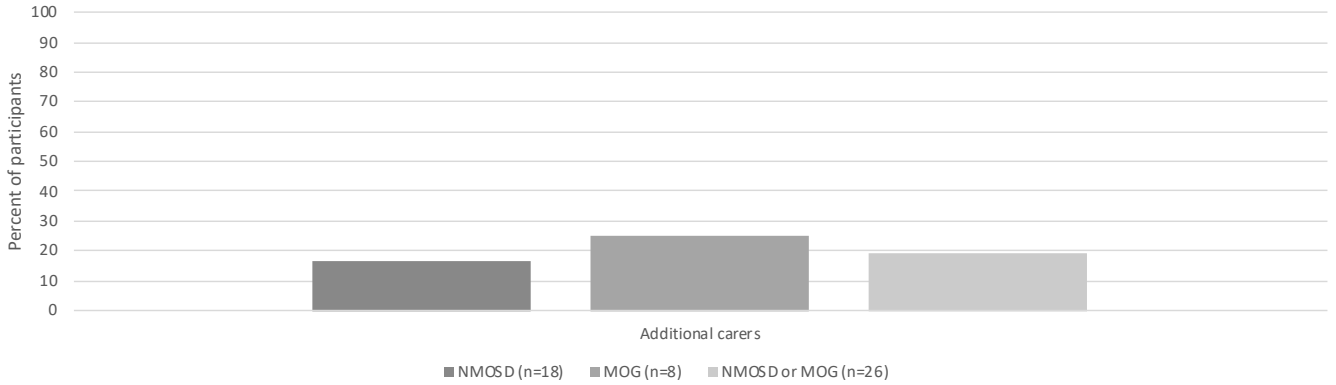

Figure 5.9: Pay for additional carers

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

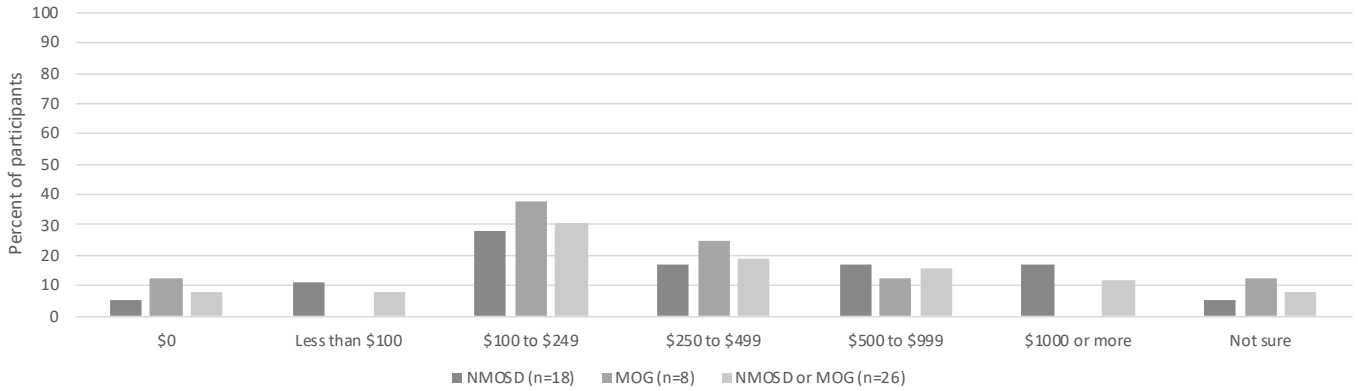

Table 5.10: Estimated monthly out of pocket expenses due to condition

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).

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%)

MOG

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 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%)

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

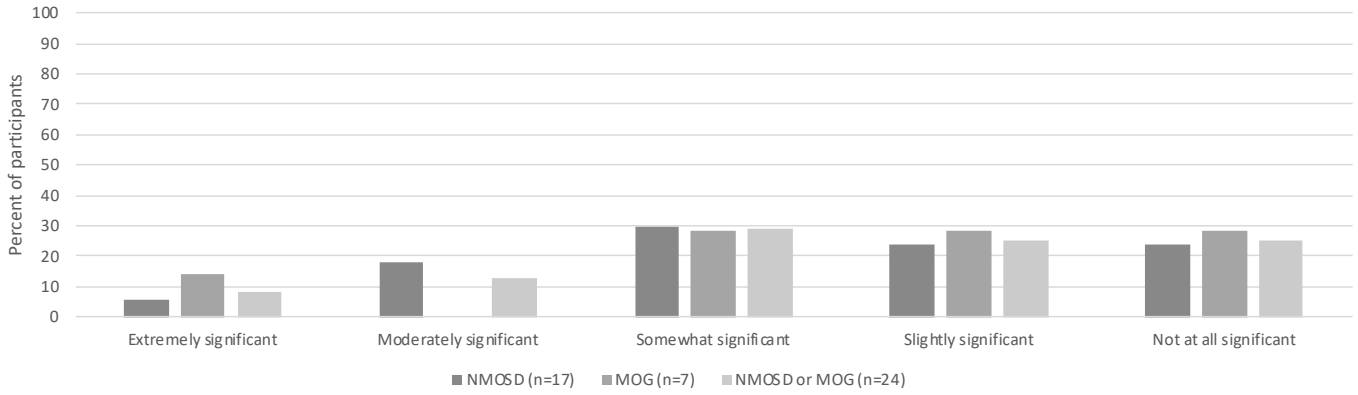

Figure 5.11: Burden of cost

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

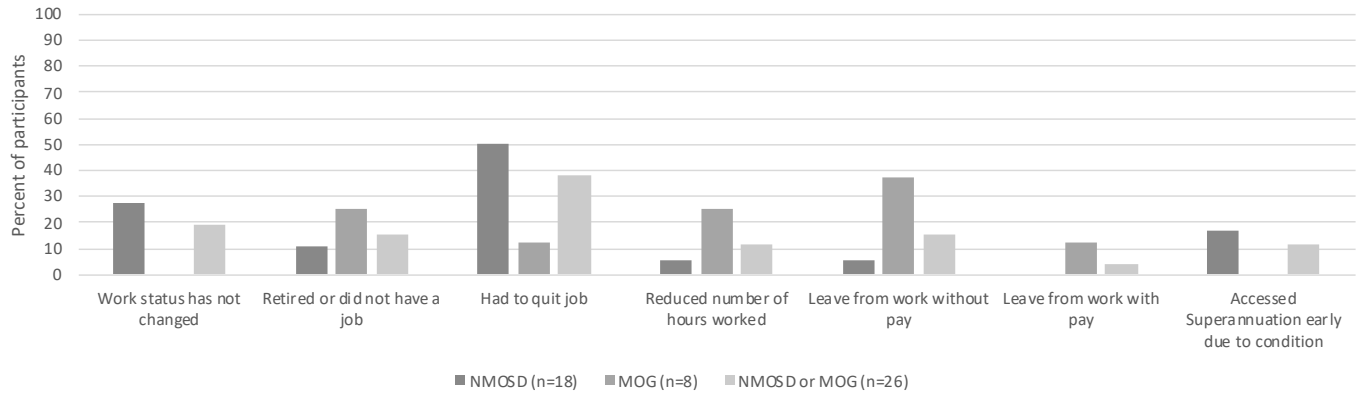

Figure 5.12: Changes to employment status

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

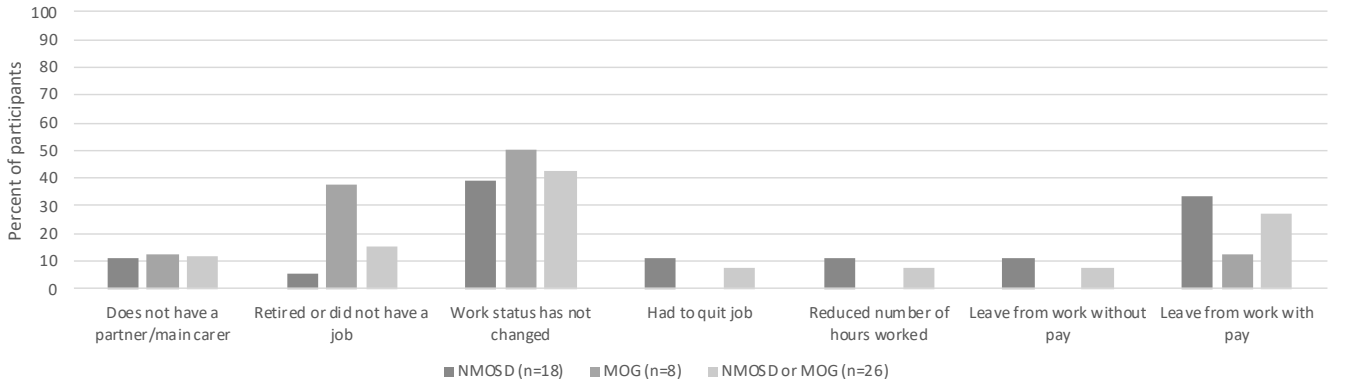

Figure 5.13: Changes to care/partner employment status

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

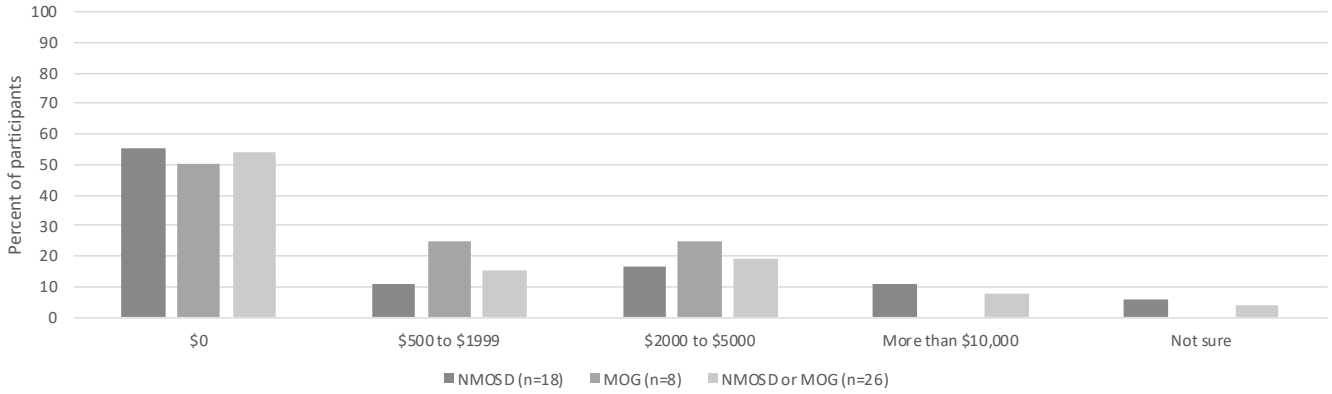

Figure 5.14: Estimated monthly loss of income

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

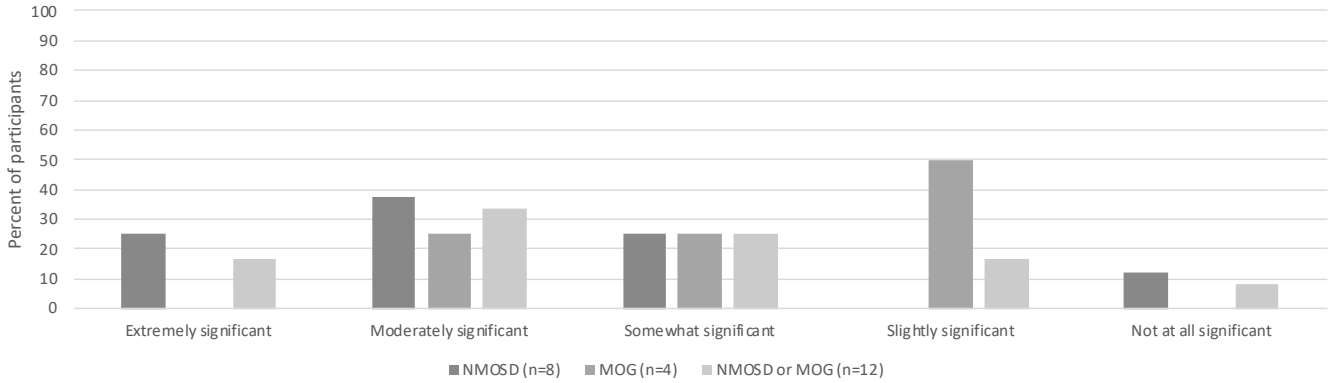

Figure 5.15: Burden of reduced income

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
Eculizumab	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

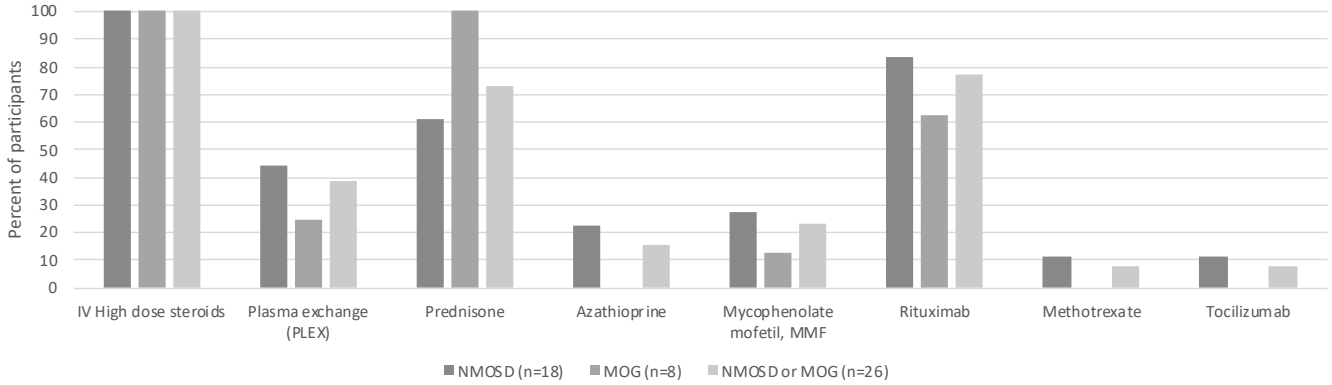

Figure 5.16: Summary of treatments

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	PLEX	Rituximab	Prednisone					
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 stu	

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

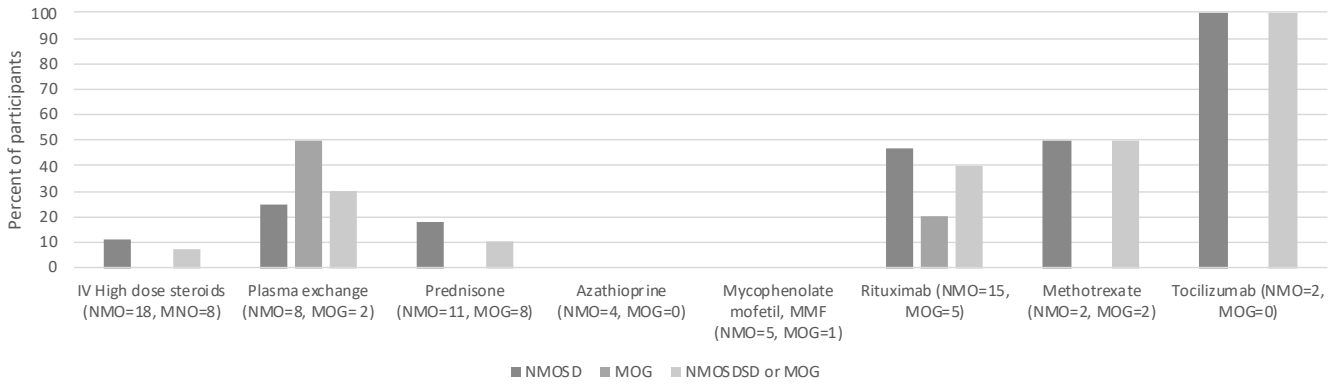

Figure 5.17: Percent of participants without side effects from treatments

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

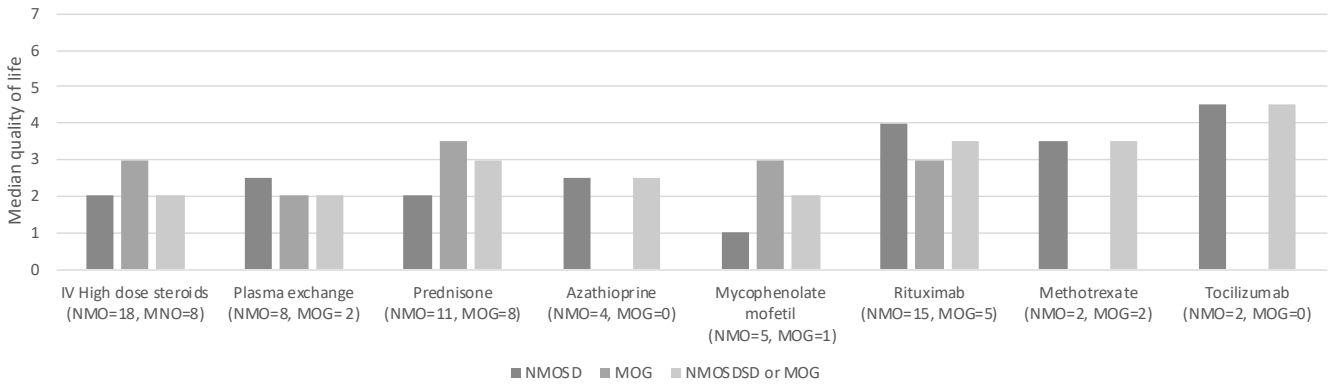

Figure 5.18: Median quality of life from treatments

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

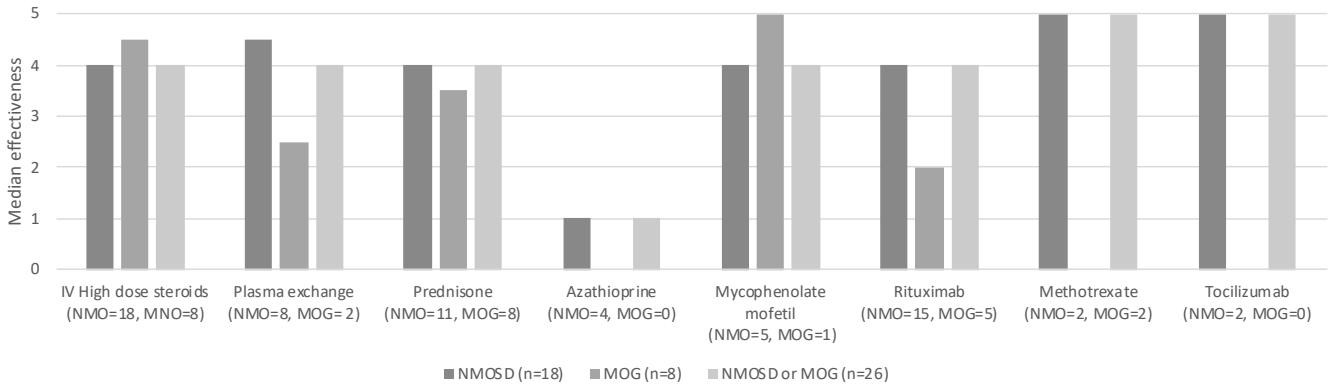

Figure 5.19: Median effectiveness of treatments

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

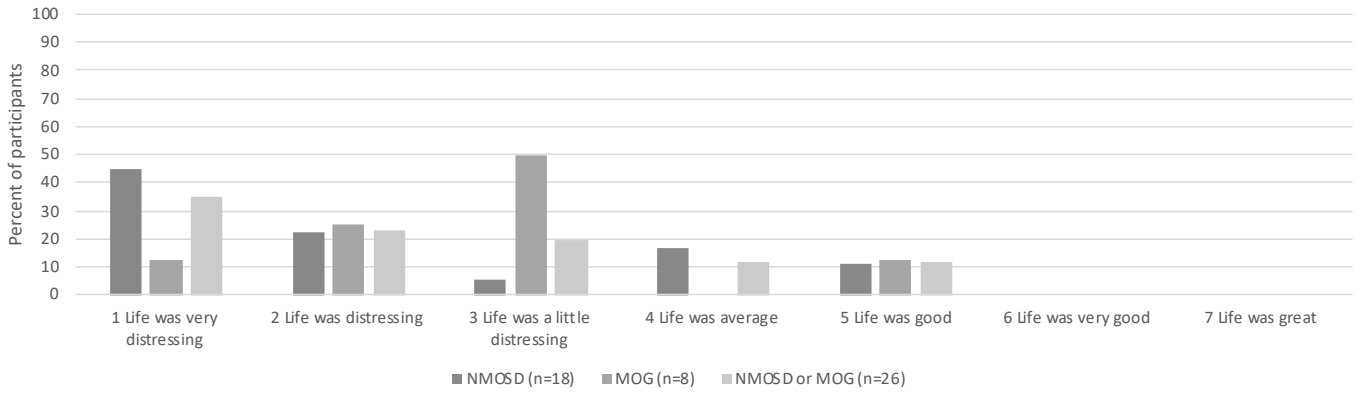

Figure 5.20: Quality of life from IV high dose steroids

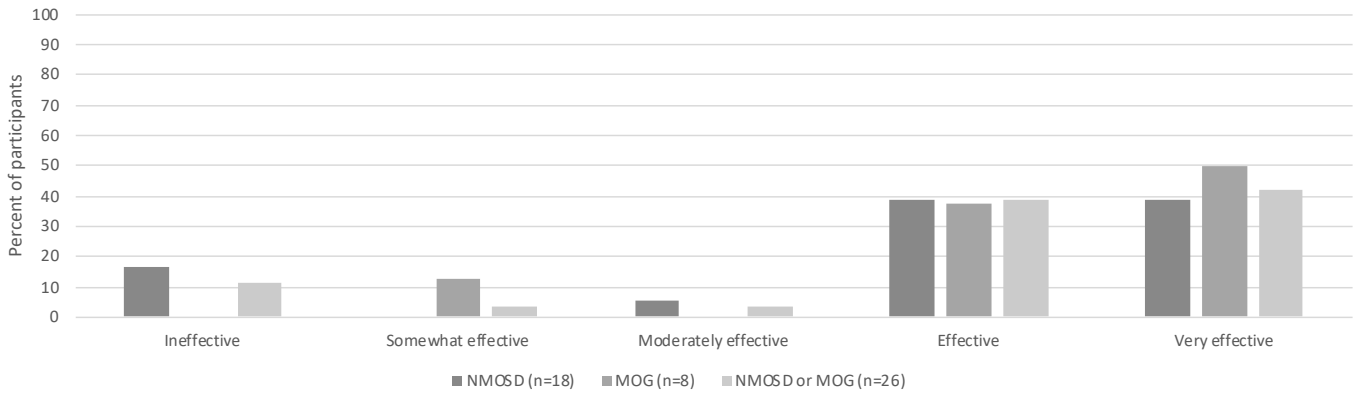

Figure 5.21: Effectiveness of IV high dose steroids

Plasma exchange (PLEX)

A total of 10 participants had plasma exchange to treat their condition. Details about quality of life (Figure5.22), 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

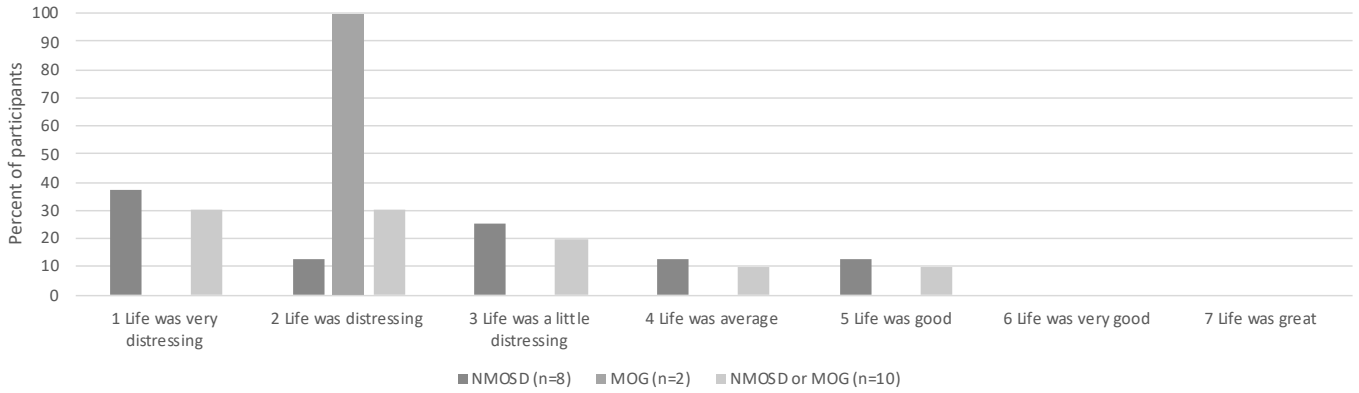

Figure 5.22: Quality of life from plasma exchange

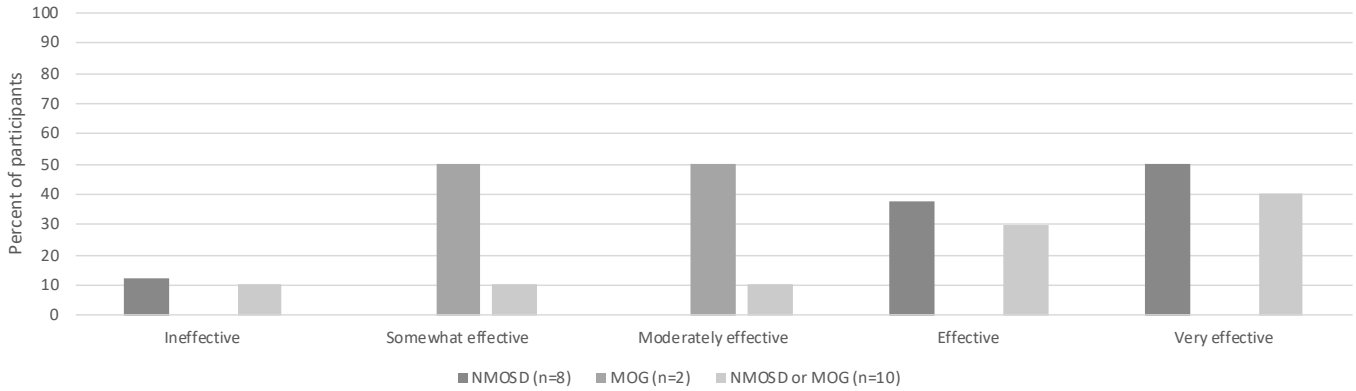

Figure 5.23: Effectiveness of plasma exchange

Prednisone

A total of 19 participants had prednisone to treat their condition. Details about quality of life (Figure5.24), 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

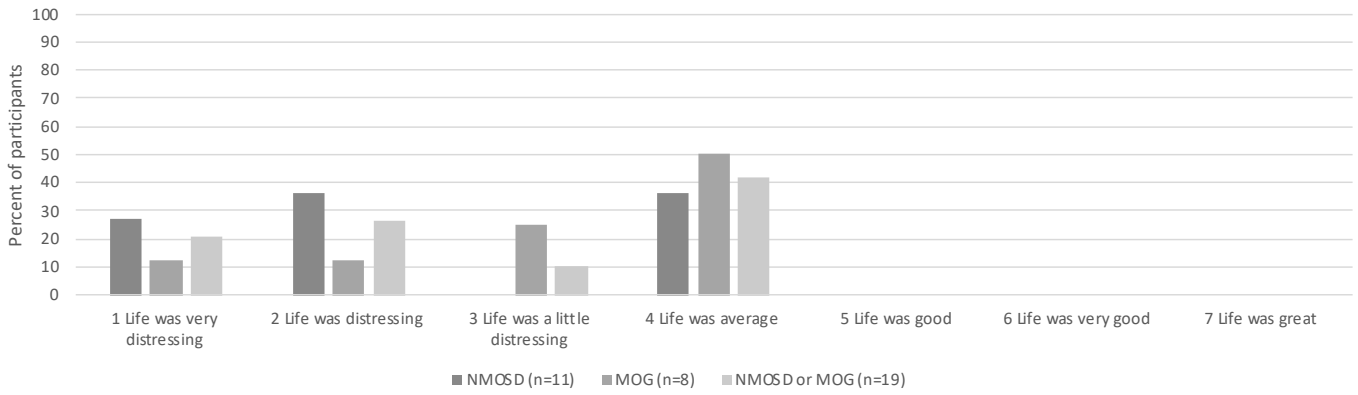

Figure 5.24: Quality of life from prednisone

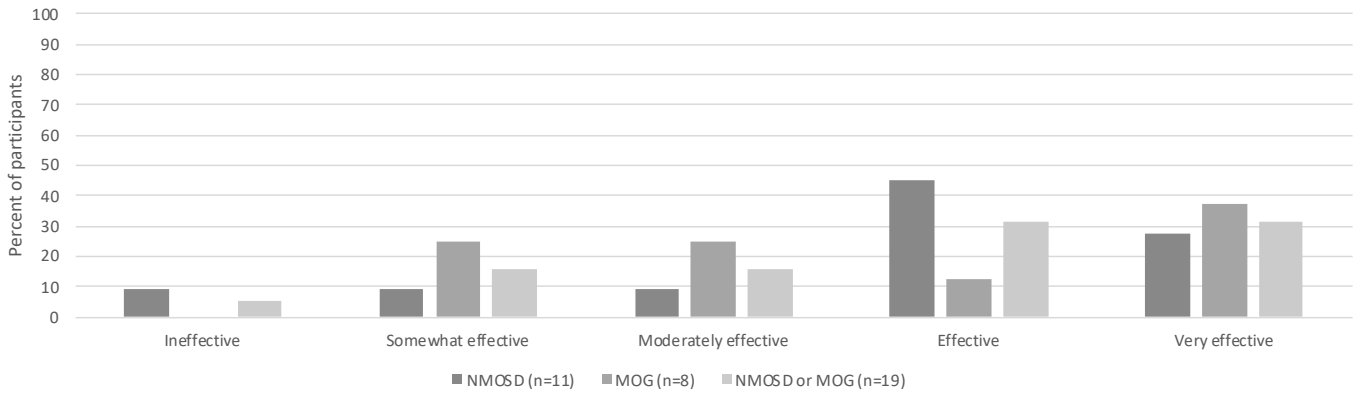

Figure 5.25: Effectiveness of prednisone

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
	No side effects	7	46.67	1	20.00	8	40.00
Side effects	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

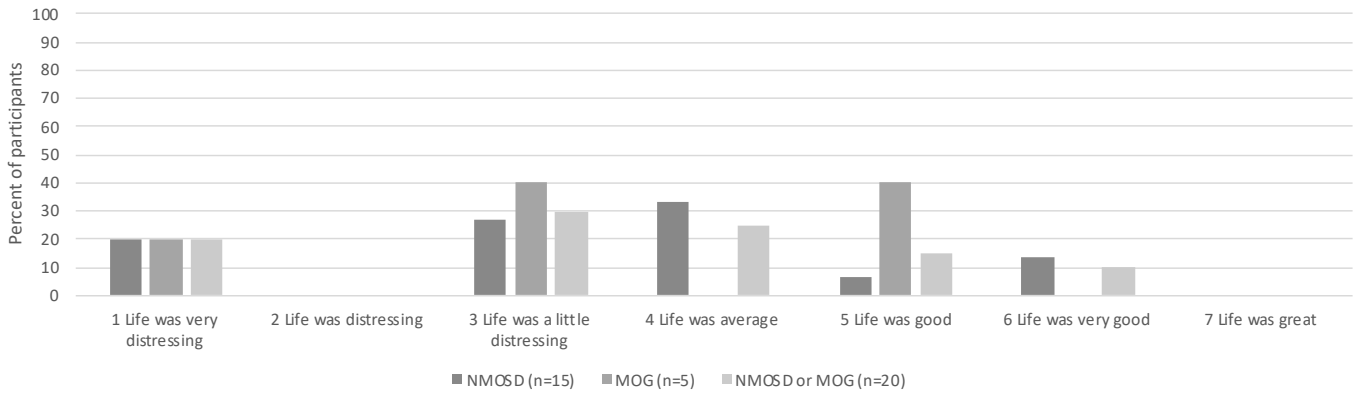

Figure 5.26: Quality of life from rituximab

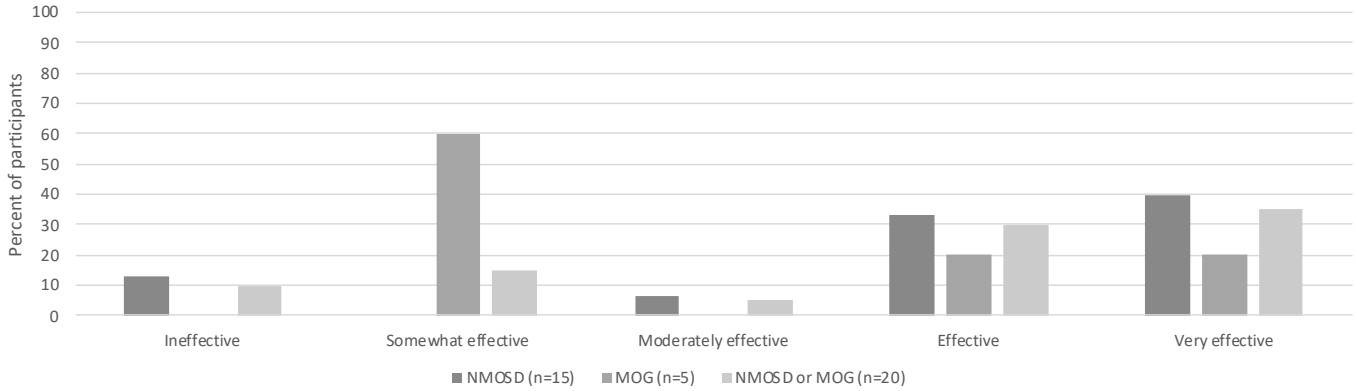

Figure 5.27a: Effectiveness of rituximab

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

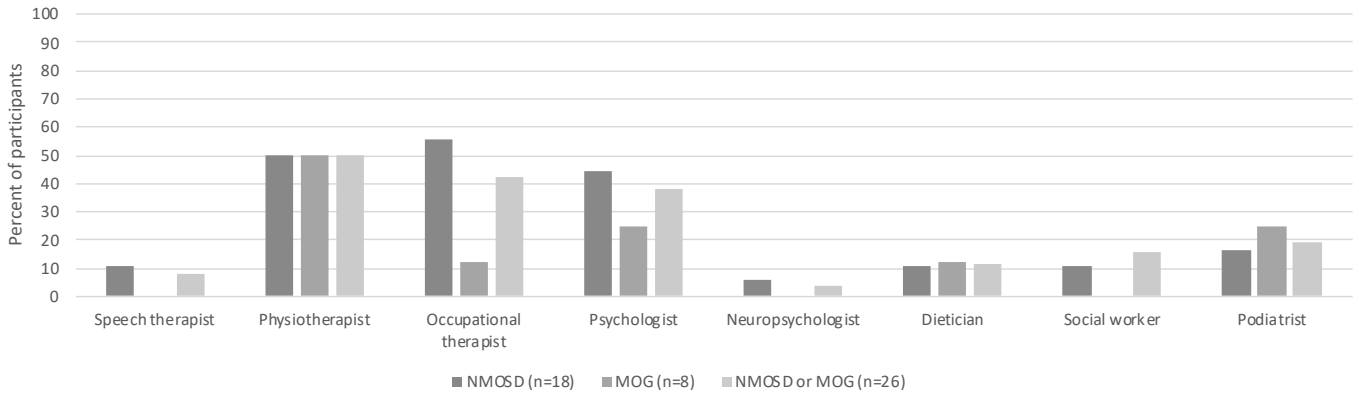

Figure 5.28: Allied health

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

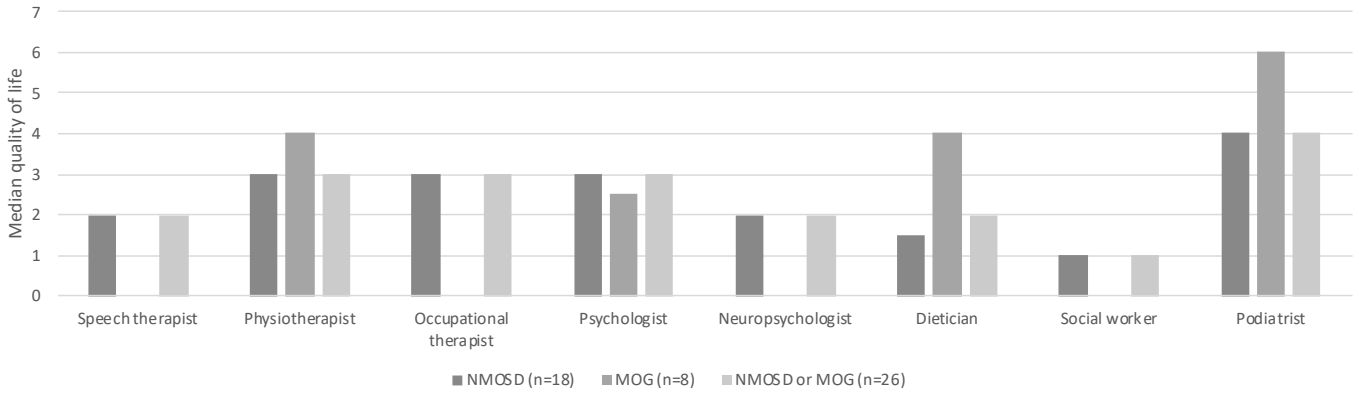

Figure 5.29: Median quality of life from allied health

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

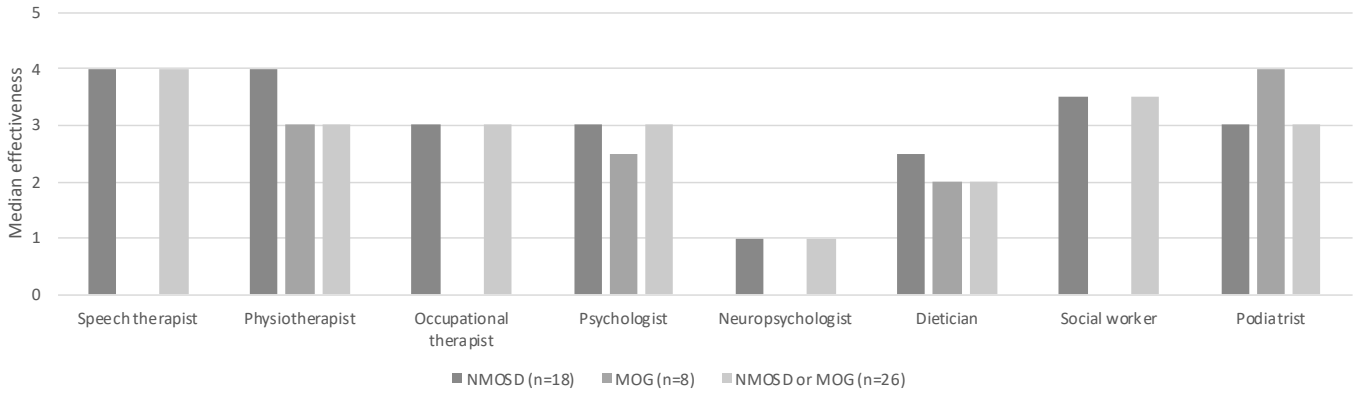

Figure 5.30: Median effectiveness of allied health

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=200, 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

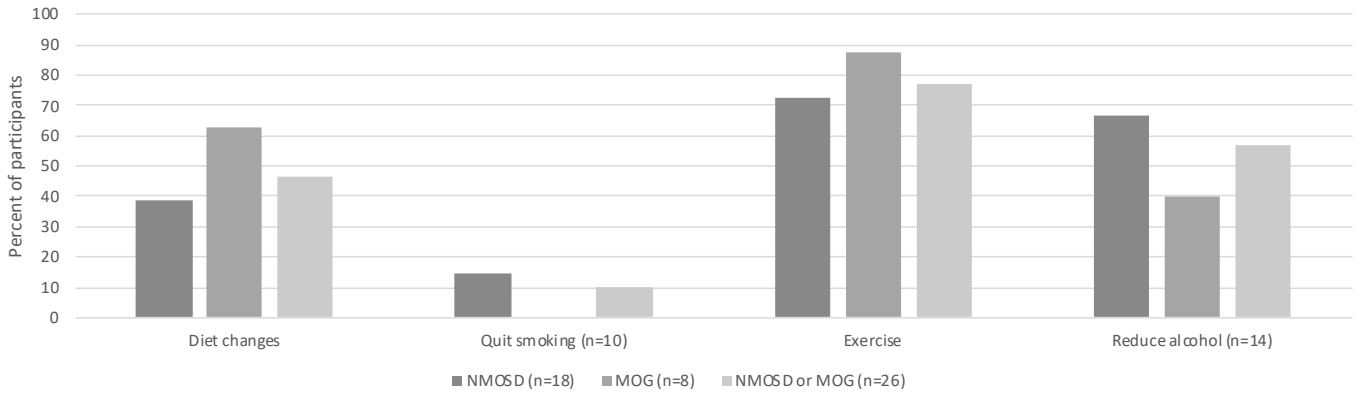

Figure 5.31: Lifestyle changes

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

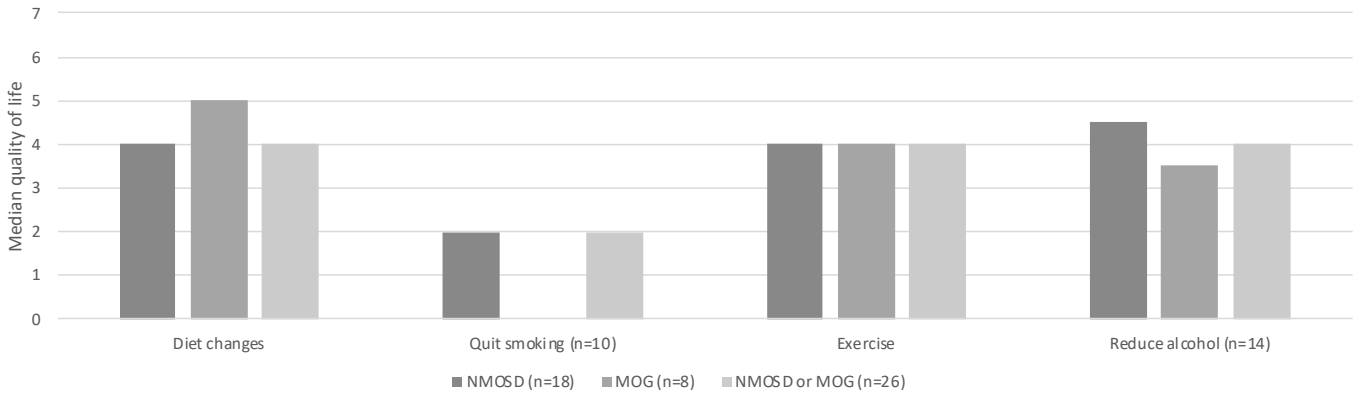

Figure 5.32: Median effectiveness of lifestyle changes

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

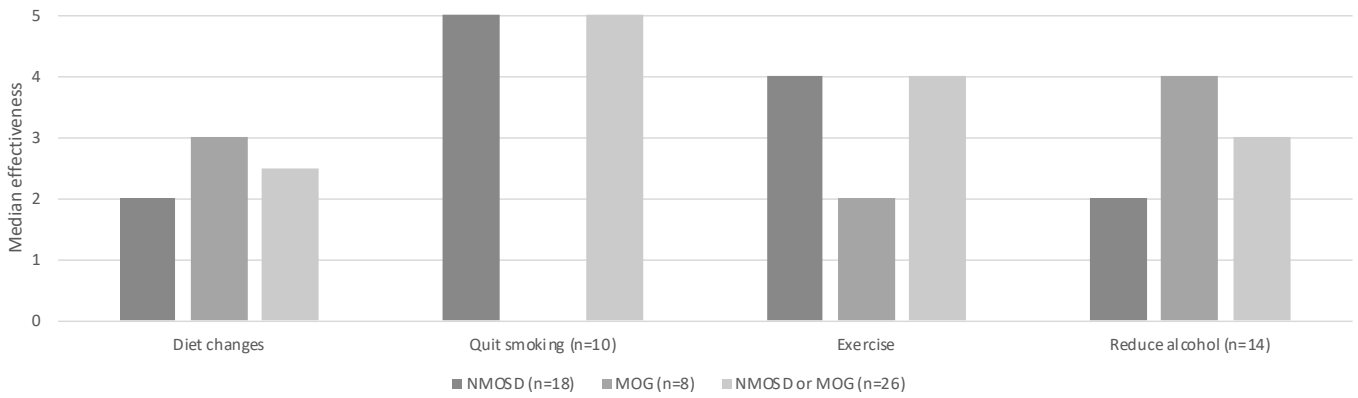

Figure 5.33: Median effectiveness of lifestyle changes

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

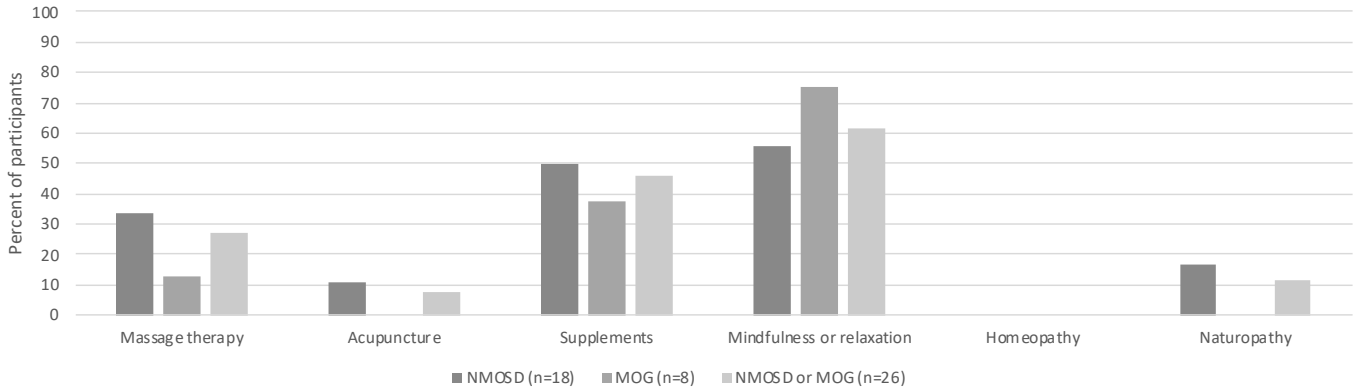

Figure 5.34: Complementary therapies

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

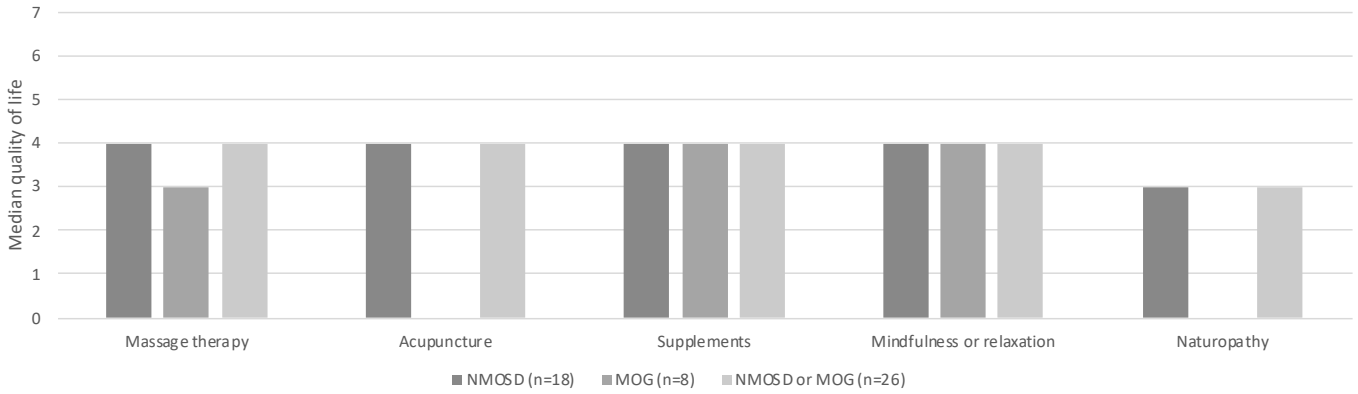

Figure 5.35: Median quality of life from complementary therapies

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

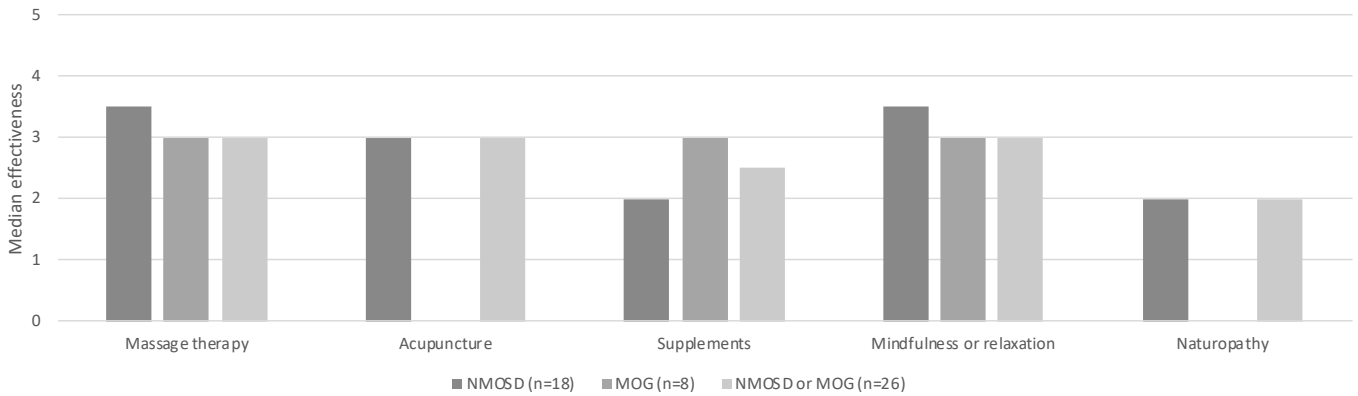

Figure 5.36: Median effectiveness from complementary therapies

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 bought 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%) bought 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%) bought 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

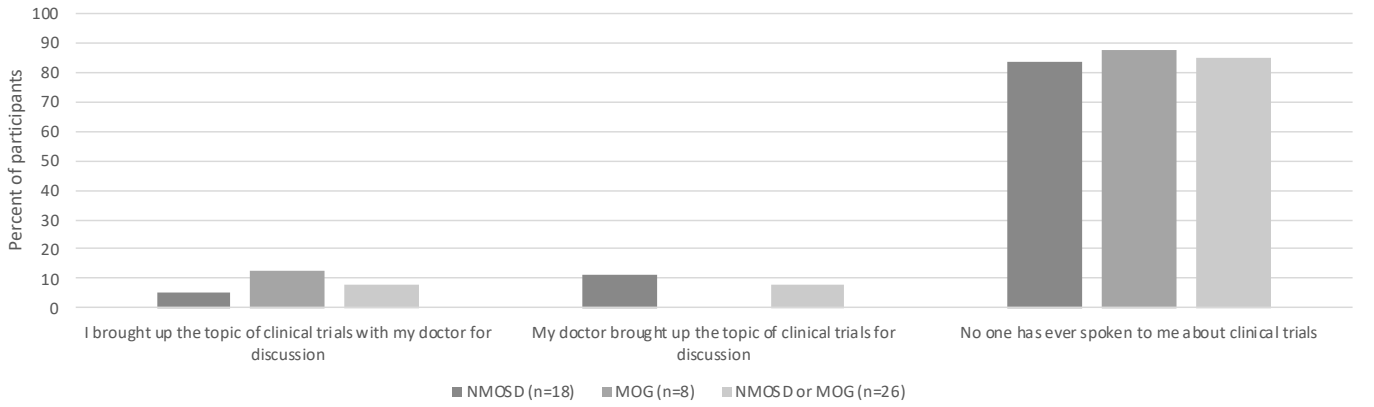

Figure 5.37: Discussions about clinical trials

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

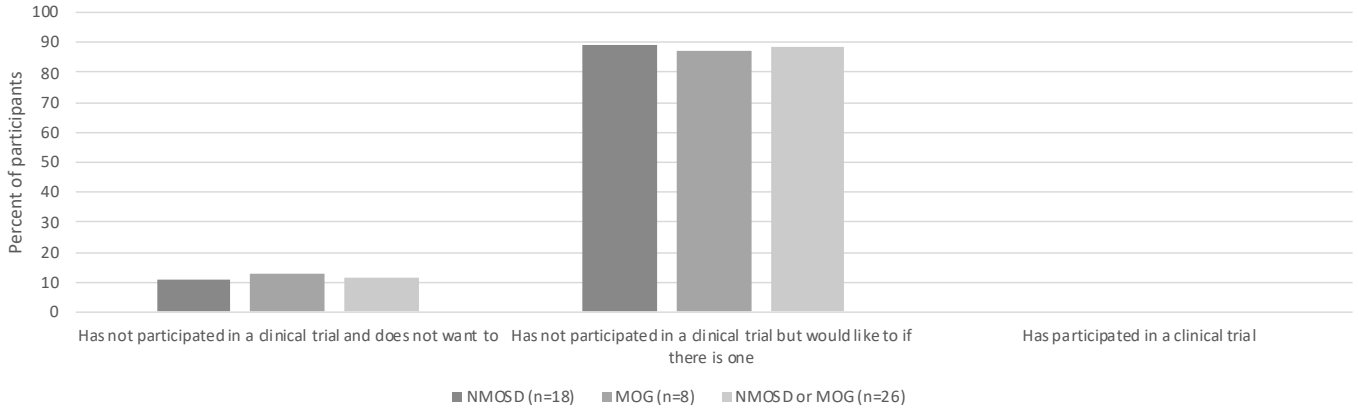

Figure 5.38: Clinical trial participation

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 tremoring 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 a 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 go physical functio	
	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 olde	
	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)

Description of mild side effects	More frequent	Less frequent
Participant provides a specific side effect as an example	More relapses	Fewer relapses
Participant describes mild side effects as those that can be self-managed and do not interfere with daily life	Good to very good physical function Aged 18 to 44	Moderate to very poor physical function

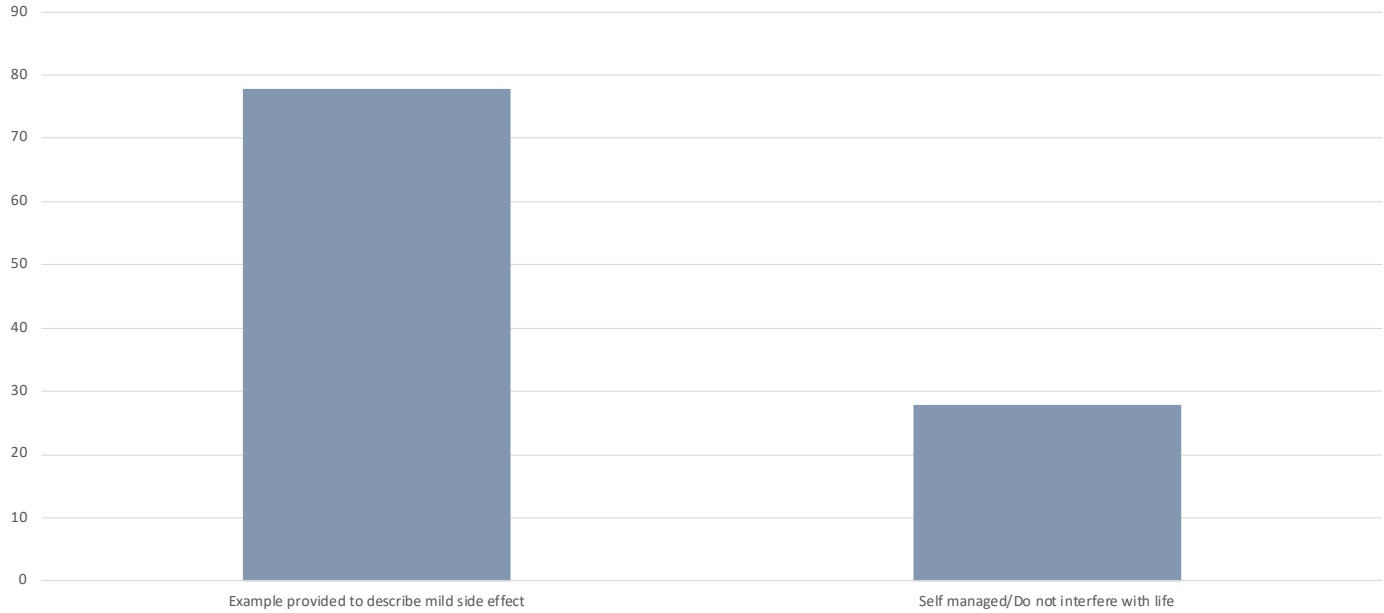

Figure 5.39: Description of mild side effects

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 go physical functio	
	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 olde	
	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 Aged 18 to 44	Higher socioeconomic status

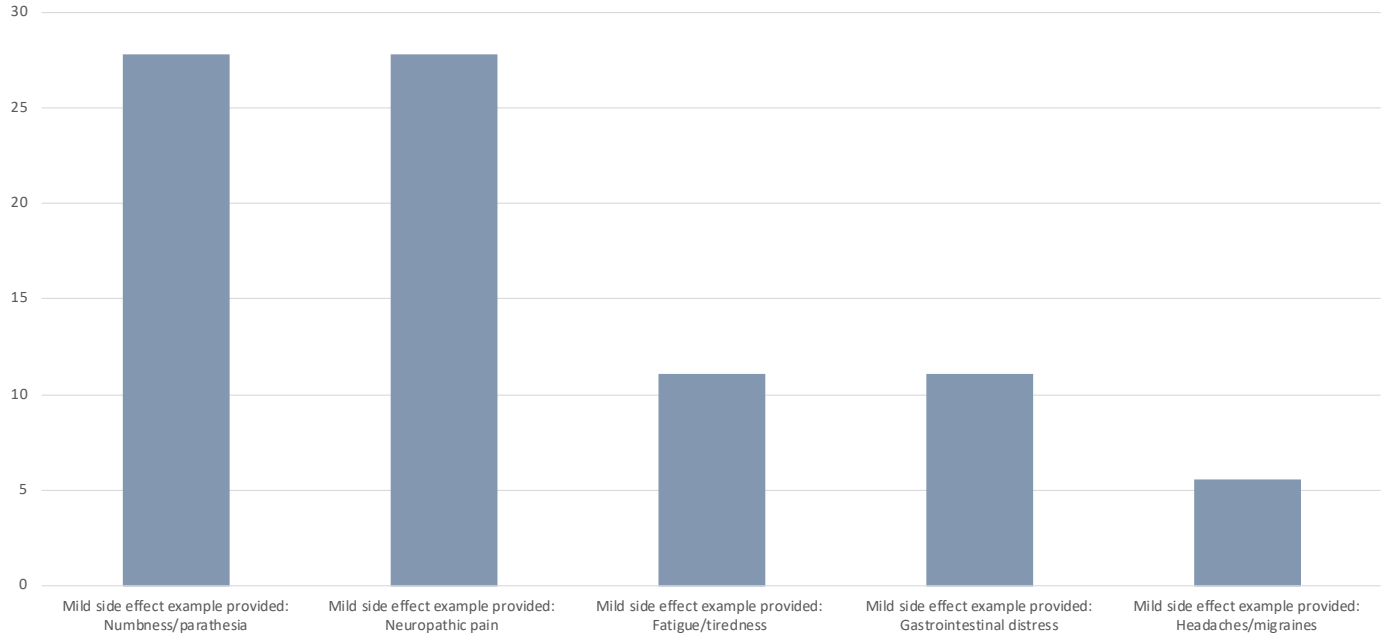

Figure 5.40: Description of mild side effects: Specific side effects

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 go physical functio	
	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 olde	
	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
Participant gives a specific example to describe severe side effects	More relapses Aged 18 to 44	Fewer relapses

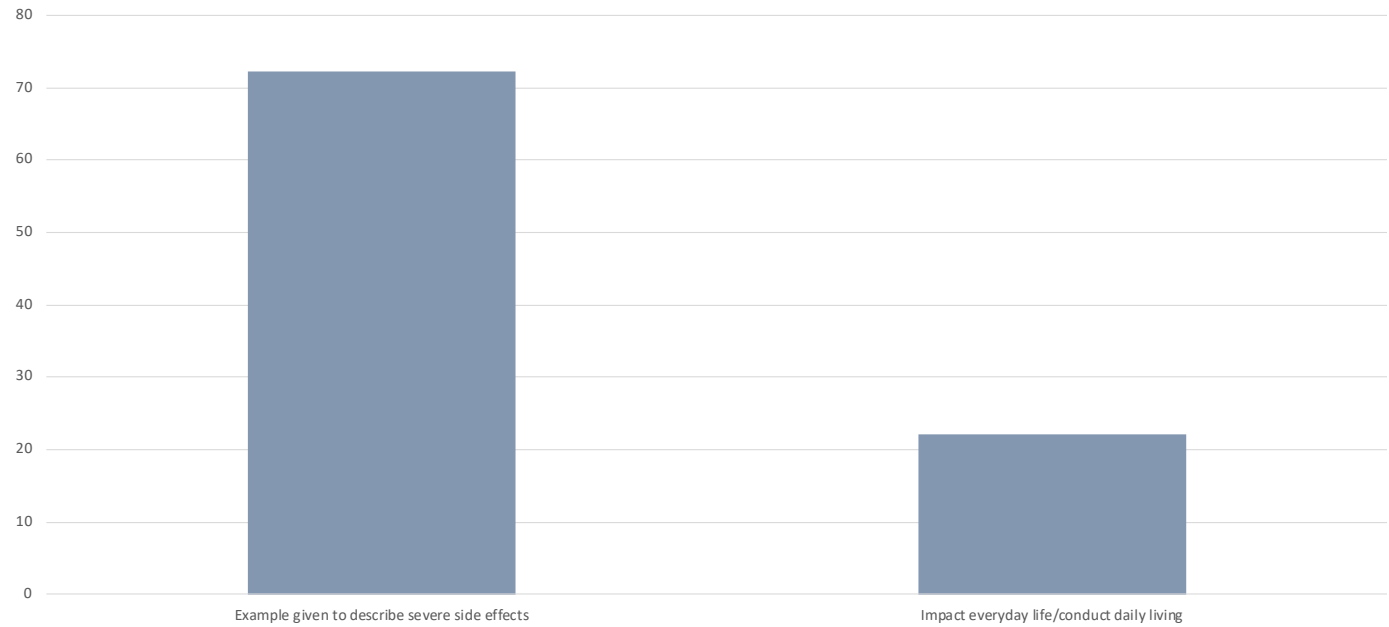

Figure 5.41: Description of severe side effects

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 go physical functio	
	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 olde	
	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)

Description of severe side effects: Specific side effect	More frequent	Less frequent
Participant describes severe side effects giving the specific example of pain	Moderate to very poor physical function Mid to low socioeconomic status	Good to very good physical function

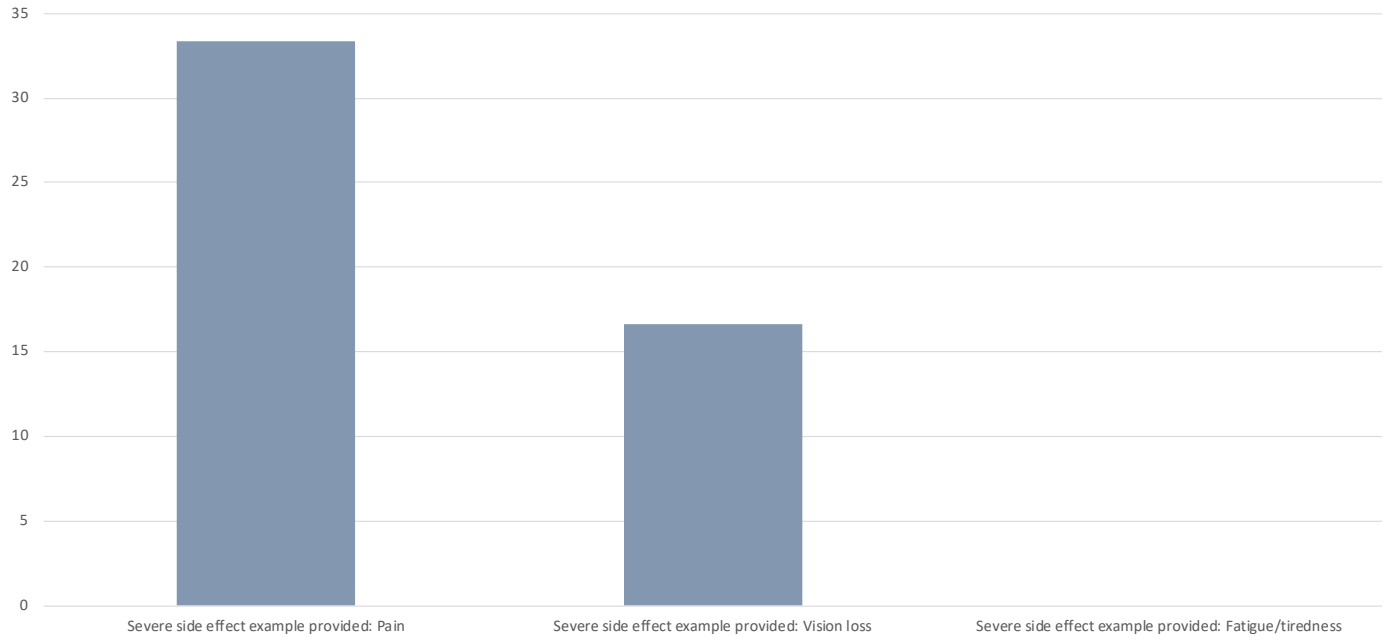

Figure 5.42: Description of severe side effects: Specific side effects

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 nauseation so that it was taking that too. With everything I had, plus the nauseation, 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 go physical functio	
	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 olde	
	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

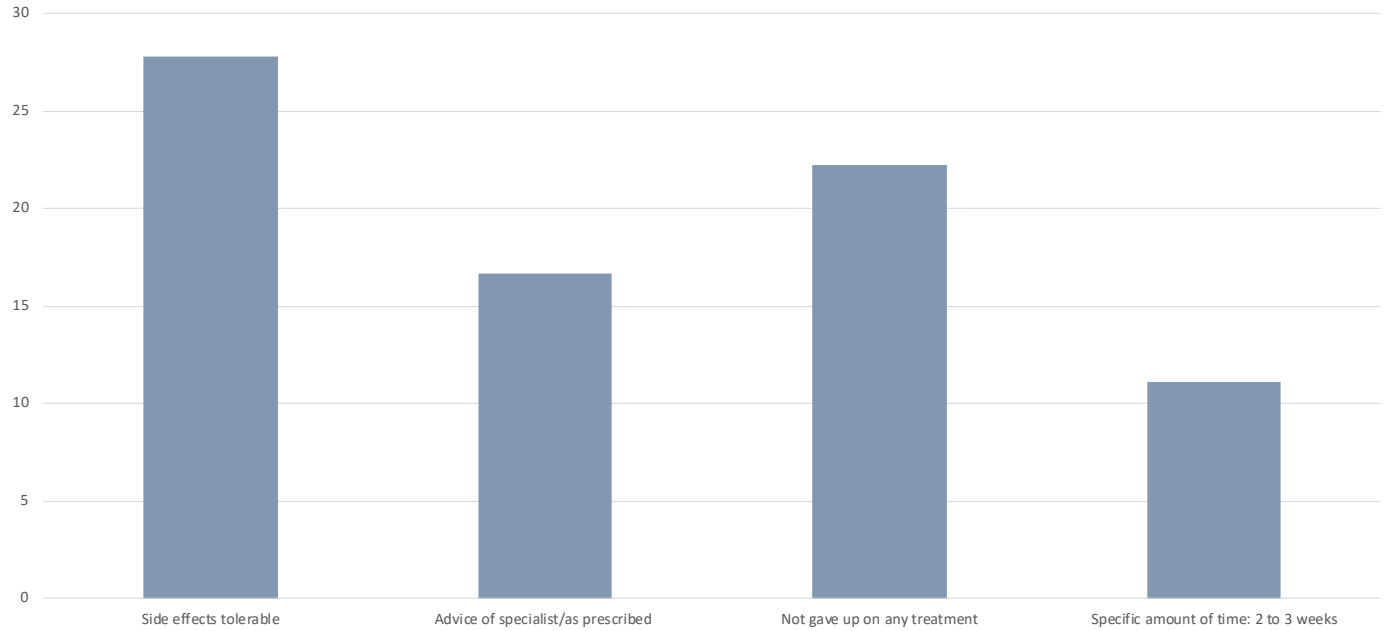

Figure 5.43: Adherence to treatment

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 go physical functio	
	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 olde	
	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

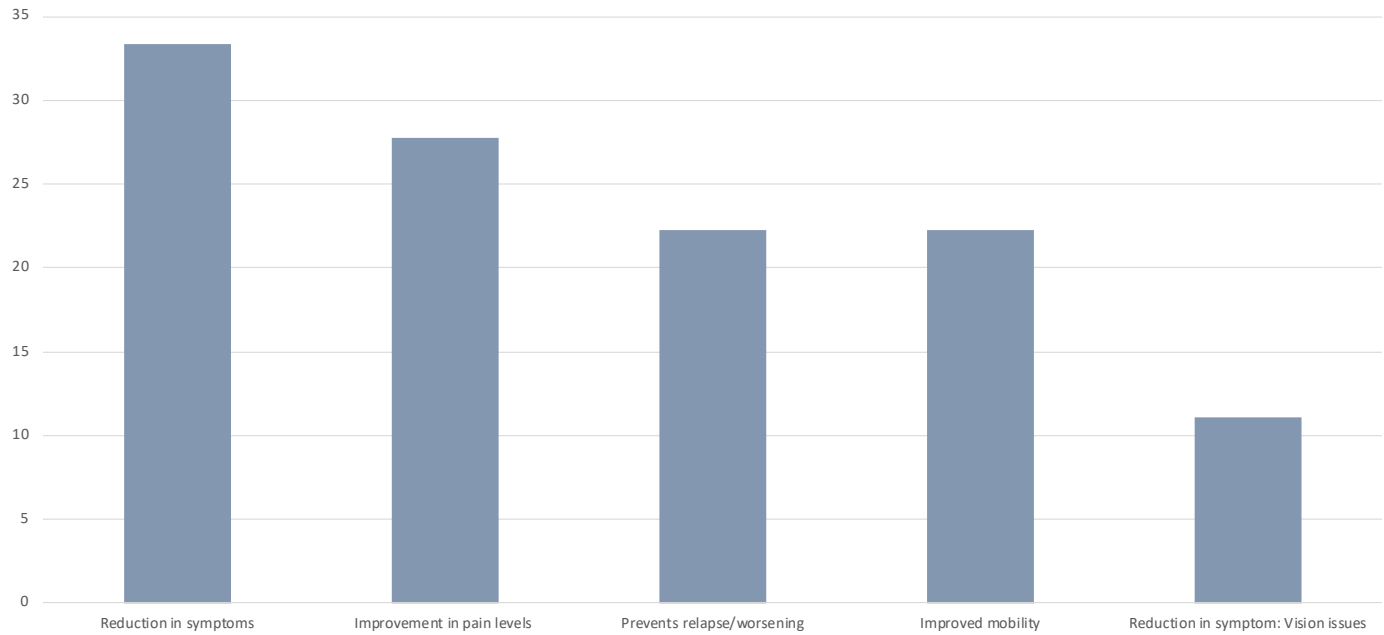

Figure 5.44: What needs to change to feel like treatment is working

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 go physical functio	
	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 olde	
	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

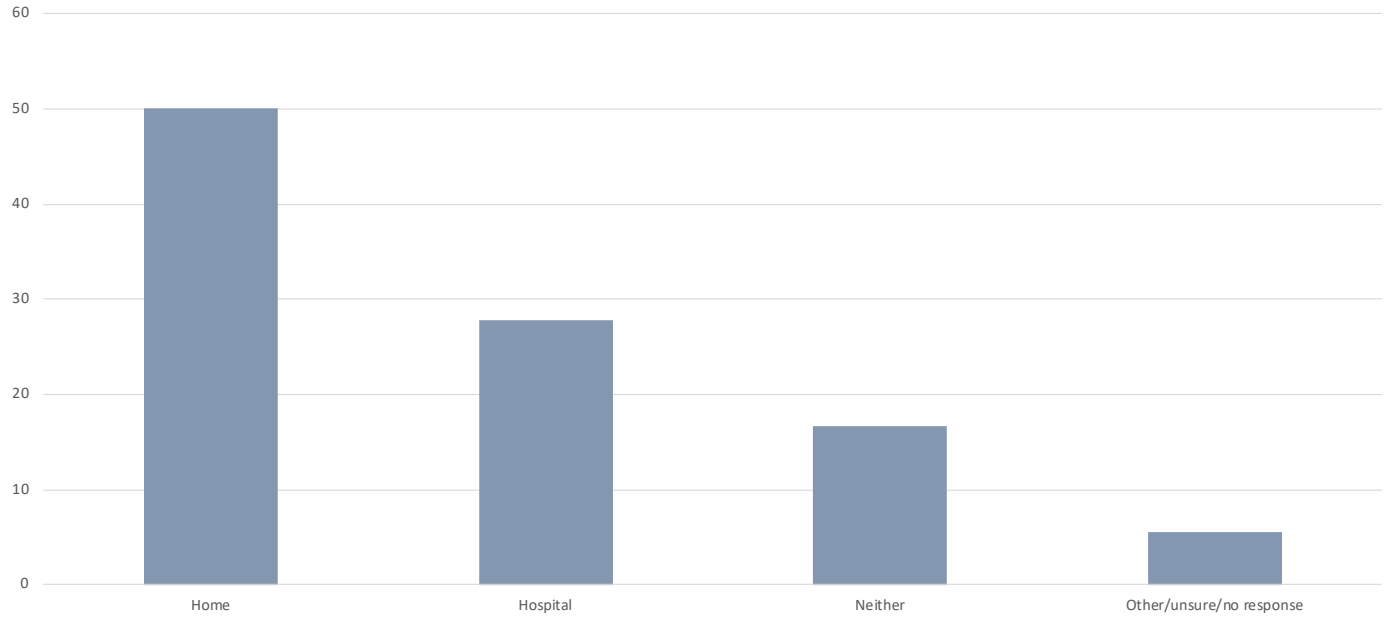

Figure 5.45: Preference for treatment

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 go physical functio	
	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 olde	
	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	*More relapses* *Low to moderate fear* *Good to very good physical function* *Aged 18 to 44*	*Fewer relapses* *High to very high fear* *Moderate to very poor physical function*

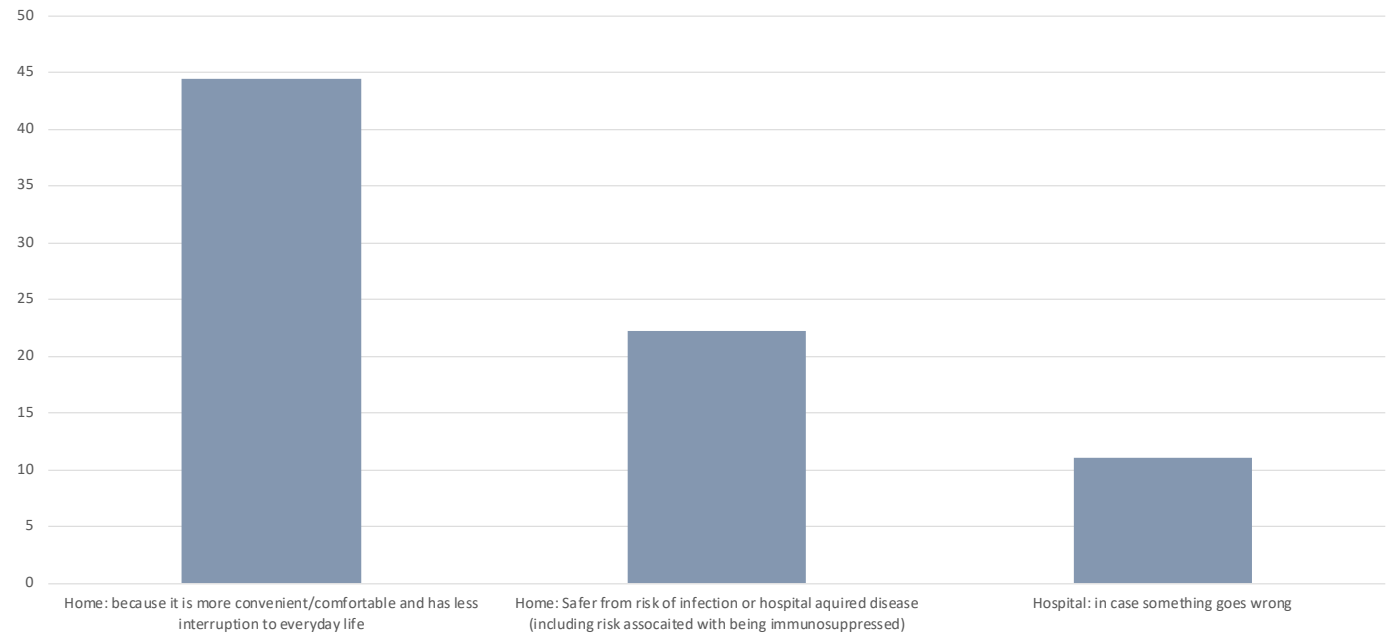

Figure 5.46: Preference for treatment: Rationale

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 go physical functio	
	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 olde	
	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

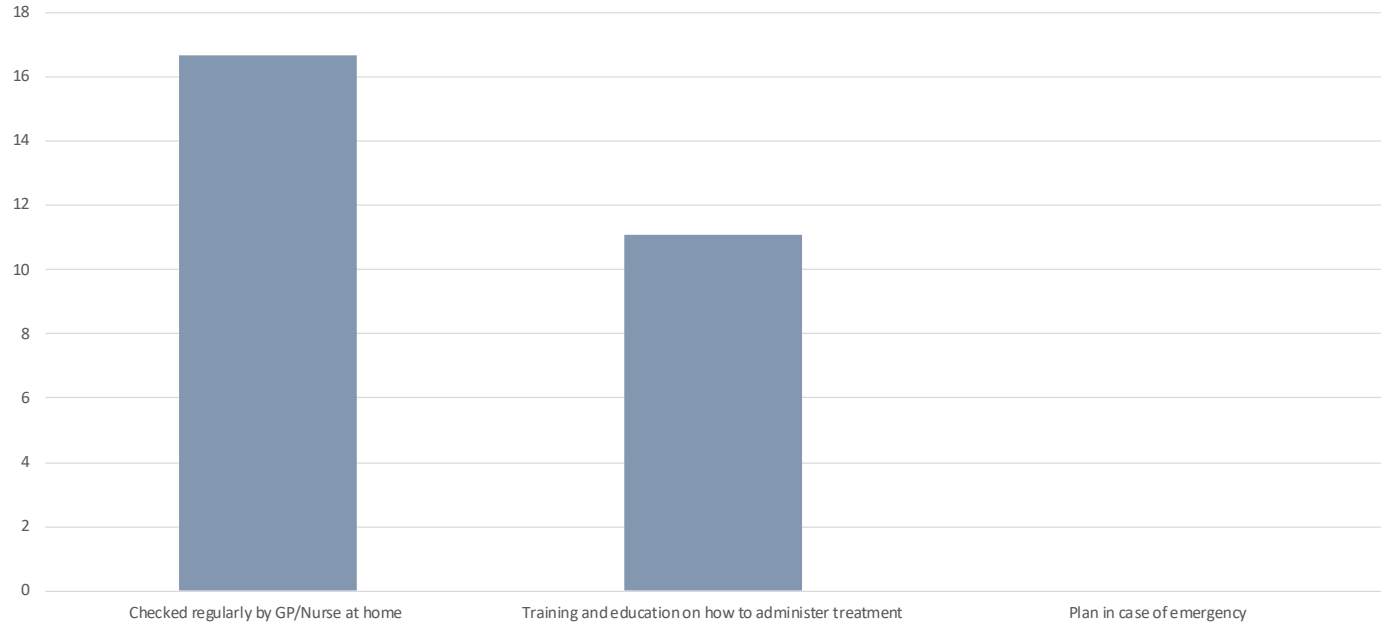

Figure 5.47: Support needed for treatment at home

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 go physical functio	
	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 olde	
	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

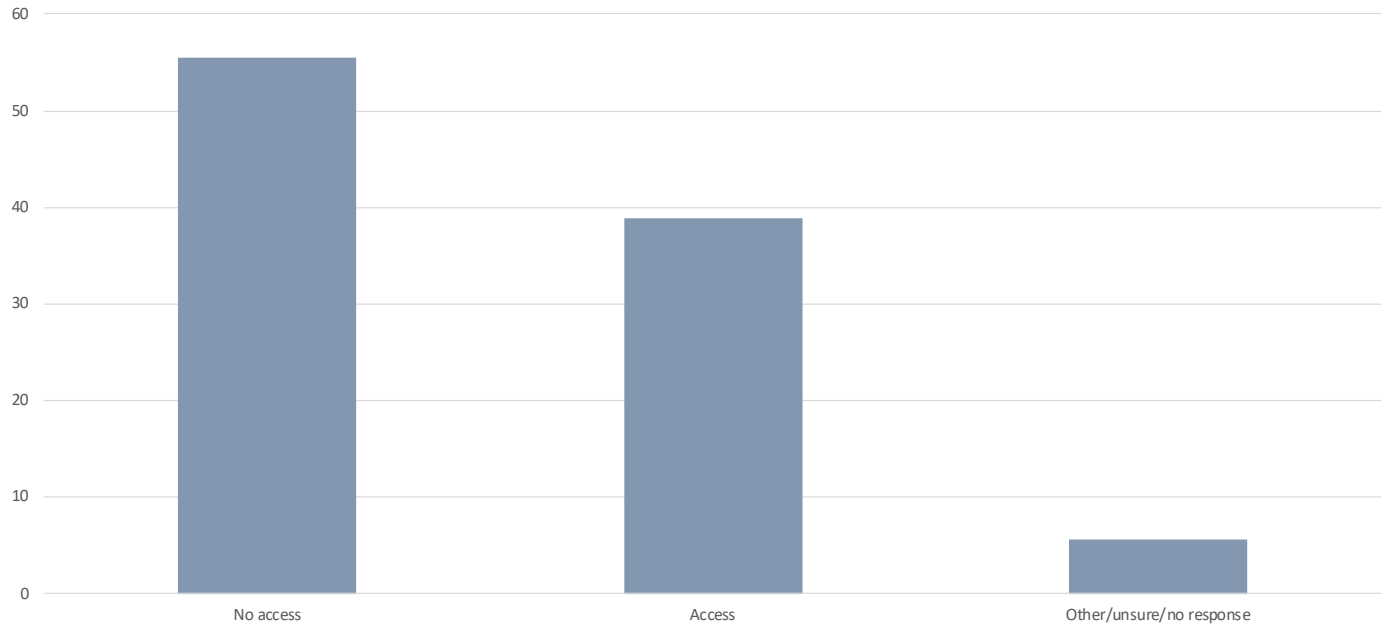

Figure 5.48: Access to telehealth or remote access

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 go physical functio	
	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 olde	
	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

Access to telehealth or remote access	More frequent	Less frequent
Participant did not receive care through telehealth or remote access (no opinion given)	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

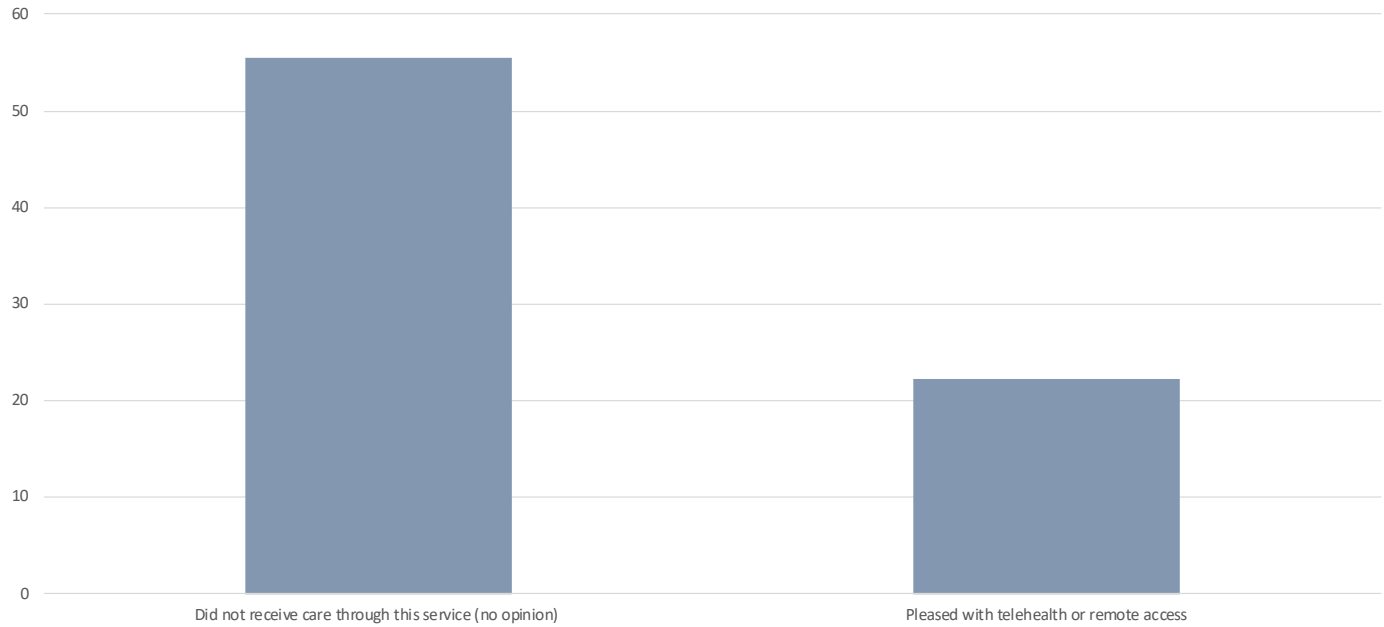

Figure 5.49: Access to telehealth or remote access: Experience

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 go physical functio	
	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 olde	
	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

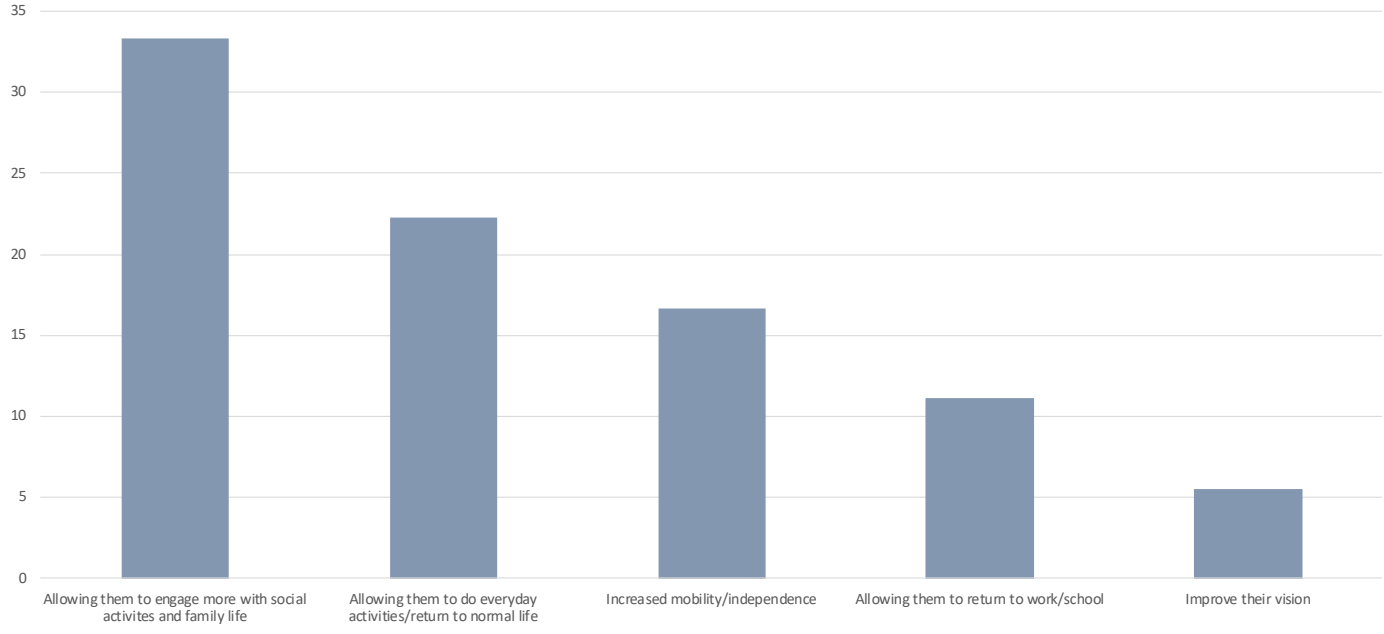

Figure 5.50: What would it mean if treatment worked

Section 6

Information and communication

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common type of information accessed by 15 participants (83.33%) was through the internet, and this was followed by Facebook (n=8, 44.44%) and information from the Guthy-Jackson Foundation (n=6, 33.33%).

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by seven participants (38.89%) was other peoples experiences.

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common response was that no information was not helpful (n=6, 33.33%)

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Overall, the most common theme was online information (n=5, 27.78%).

Information preferences: Rationale

The most common theme reason for their information preference was due to being able to digest information at their own pace (n=7, 38.89%).

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common times that participants described being receptive to receiving information was from the beginning (diagnosis) (n=7, 38.89%), and participants describing being receptive to information after a specific amount of time had passed (n=7, 38.89%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall negative experience (n=11, 61.11%) followed by five participants (27.78%) who described an overall positive experience.

Healthcare professional communication: Reasons for experience

There were eight participants (44.44%) that described health professional communication as limited in relation to their understanding of the condition. Where participants described a positive experience, this related to communication being holistic (two way, supportive and comprehensive conversations) (n=5, 27.78%).

Partners in health

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a moderate ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had excellent recognition and management of symptoms.

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals. Participants with NMOSD were most commonly given information about treatment options (n=10, 55.56%), and disease management (n=6, 33.33%). There were five participants (27.78%) that received very little information from healthcare professionals.

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. Participants with NMOSD most commonly searched for information about disease management (n=16, 88.89%), disease cause (n=15, 83.33%), treatment options (n=12, 66.67%), complementary therapies (n=11, 61.11%), and physical activity (n=10, 55.56%). Half of the participants looked for information about how to interpret test results, dietary information, and psychological/social support (n=9, 50.00%).

Information gaps: participants with NMOSD

The topic most often given to participants by healthcare professionals and not searched for independently was about treatment options (n = 5, 27.78%).

The topics most commonly given to participants by healthcare professionals and searched for independently were disease management (n=5, 27.78%), and treatment options (n=5, 27.78%).

Topics most often not given by health professional and not searched for independently were clinical trials (n=12, 66.67%), hereditary considerations (n=10, 55.56%), and dietary information (n=9, 50.00%).

The most common topics that were searched for and not given by a healthcare professional were disease cause (n=13, 72.22%), disease management (n=11, 61.11%), complementary therapies (n=11, 61.11%), and physical activity (n=10, 55.56%). Half of the participants searched for how to interpret test results, and dietary information without receiving information from healthcare professionals (n=9, 50.00%).

Most accessed information

Participants were asked to rank which information source that they accessed most often. Participants with NMOSD accessed information from non-profits organisations, charities, or patient organisations most often, followed by medical journals, and from the government least often

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. Participants were asked if they had accessed it, and if they had accessed it, how useful it was. There were nine participants with NMOSD (50.00%) that had accessed My Health Record, seven participants (38.89%) that had not. There was one participant (5.56%) that wasn't sure, and one participant (5.56%) that's did not know what it is.

Of those that had accessed My Health Record, there were three participants (33.33%) that thought the usefulness was very poor, two participants (22.22%) that thought it was poor, and four participants (44.44%) found it acceptable)

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common type of information accessed by 15 participants (83.33%) was through the internet, and this was followed by Facebook (n=8, 44.44%) and information from the Guthy-Jackson Foundation (n=6, 33.33%).

Participant describes accessing information through the internet in general

Mainly Google. I sought out possible causes. I sought out whether vaccines have anything to do with it. That's just recent. I sought out diets that might be good. That's just recent too. Participant NMO_002

Pretty much just the internet and I've joined some Facebook groups of people that have it. Participant NMO_008

Goodness. Pretty much YouTube, Google. There wasn't really that much at that particular time. Just watching I suppose YouTube more so, I got more things out of, but still wasn't that great at that time. Participant NMO_012

Participant describes accessing information primarily through Facebook

The biggest one was to get onto the support page, their NMO support page on Facebook with the registered nurses and just listening to everyone else, and seeing what everyone else was going through, that's where I got all the information from. Participant NMO_009

Most of my information comes through Facebook, on the NMO Australia site and anything related to that, like they'll put up studies and anything that's going ahead. Participant NMO_011

I'm on the Facebook page, the NMO Australian website. There's a lot of people with NMO who are on there. Participant NMO_015

Participant describes accessing information from a specific health charity: Guthy-Jackson foundation

I sought out some information from the Guthy-Jackson Charitable Foundation. I don't know if you've heard of them. They're pretty big. Participant NMO_002

It was purely while I was in hospital, I happened to find the Guthy Jackson. Participant NMO_006

Mostly the Guthy-Jackson Foundation in the States we could say were the first NMO-- Anyone in the world that was like a foundation for NMO. Participant NMO_016

Participant describes accessing information primarily through journals (research articles)

Medical journal, NMO support group. Back then I haven't had to sign up but I never really read anything because I didn't want to read too much and then think too much. Participant NMO_001

I try my best to read-- It takes me a while with my eyes, but to read like research articles from medical journals. Participant NMO_005

More recently, I've found some information from some journal articles online, and just some Facebook support groups and stuff, less academic stuff, but more seeing how my peers are going, or how they're dealing with things has been pretty useful because I didn't have that when I was diagnosed. Participant NMO_010

Participant describes primarily accessing information through treating clinician

The general information that I've mainly got is through my MS specialist, and on the internet, and the Guthy-Jackson Foundation, actually. Participant NMO_004

When I was first diagnosed, I looked for information everywhere, my neurologist, my GP, online, and there really wasn't anything available. Participant NMO_010

My neuro immunologist and neurologist gave me really good information and they sat me down a few times for a few hours and just basically went through everything, but it's the nurses when I went to have any infusions, so they were really good in the department. Participant MOG_006

Participant describes primarily accessing information through other patient's experience

I'm also in a group on Facebook where people write about themselves, or any treatments, or anything new that's coming up, so it's mostly all been from me looking on-- I guess, on the internet. Participant NMO_005

The biggest one was to get onto the support page, their NMO support page on Facebook with the registered nurses and just listening to everyone else, and seeing what everyone else was going through, that's where I got all the information from. Participant NMO_009

More recently, I've found some information from some journal articles online, and just some Facebook support groups and stuff, less academic stuff, but more seeing how my peers are going, or how they're dealing with things has been pretty useful because I didn't have that when I was diagnosed. Participant NMO_010

Table 6.1: Access to information

Information accessed	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes accessing information through the internet in general	15	83.33	8	88.89	7	77.78	8	100.00	7	70.00	6	66.67	9	100.0
Participant describes accessing information primarily through Facebook	8	44.44	3	33.33	5	55.56	4	50.00	4	40.00	3	33.33	5	55.56
Participant describes accessing information from a specific health charity: Guthy-Jackson foundation	6	33.33	2	22.22	4	44.44	3	37.50	3	30.00	4	44.44	2	22.22
Participant describes accessing information primarily through journals (research articles)	4	22.22	3	33.33	1	11.11	3	37.50	1	10.00	1	11.11	3	33.33
Participant describes primarily accessing information through treating clinician	3	16.67	3	33.33	0	0.00	2	25.00	1	10.00	2	22.22	1	11.11
Participant describes primarily accessing information through other patient's experience	3	16.67	2	22.22	1	11.11	2	25.00	1	10.00	1	11.11	2	22.22

Information accessed	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes accessing information through the internet in general	15	83.33	8	80.00	7	87.50	5	83.33	10	83.33	6	42.86	9	81.82
Participant describes accessing information primarily through Facebook	8	44.44	4	40.00	4	50.00	3	50.00	5	41.67	3	42.86	5	45.45
Participant describes accessing information from a specific health charity: Guthy-Jackson foundation	6	33.33	3	30.00	3	37.50	3	50.00	3	25.00	3	14.29	3	27.27
Participant describes accessing information primarily through journals (research articles)	4	22.22	0	0.00	4	50.00	1	16.67	3	25.00	3	42.86	1	9.09
Participant describes primarily accessing information through treating clinician	3	16.67	1	10.00	2	25.00	0	0.00	3	25.00	1	42.86	2	18.18
Participant describes primarily accessing information through other patient's experience	3	16.67	1	10.00	2	25.00	1	16.67	2	16.67	2	28.57	1	9.09

Information accessed	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes accessing information through the internet in general	15	83.33	8	80.00	7	87.50	5	83.33	10	83.33	6	42.86	9	81.82
Participant describes accessing information primarily through Facebook	8	44.44	4	40.00	4	50.00	3	50.00	5	41.67	3	42.86	5	45.45
Participant describes accessing information from a specific health charity: Guthy-Jackson foundation	6	33.33	3	30.00	3	37.50	3	50.00	3	25.00	3	14.29	3	27.27
Participant describes accessing information primarily through journals (research articles)	4	22.22	0	0.00	4	50.00	1	16.67	3	25.00	3	42.86	1	9.09
Participant describes primarily accessing information through treating clinician	3	16.67	1	10.00	2	25.00	0	0.00	3	25.00	1	42.86	2	18.18
Participant describes primarily accessing information through other patient's experience	3	16.67	1	10.00	2	25.00	1	16.67	2	16.67	2	28.57	1	9.09

Table 6.2: Access to information (Subgroup variations)

Information accessed	More frequent	Less frequent
Participant describes accessing information through the internet in general	Low to moderate fear Good to very good physical function	High to very high fear Moderate to very poor physical function Aged 18 to 44
Participant describes accessing information primarily through Facebook	More relapses Good to very good physical function	Fewer relapses Moderate to very poor physical function
Participant describes accessing information from a specific health charity: Guthy-Jackson foundation	More relapses Moderate to very poor physical function Mid to low socioeconomic status	Fewer relapses Good to very good physical function Aged 18 to 44

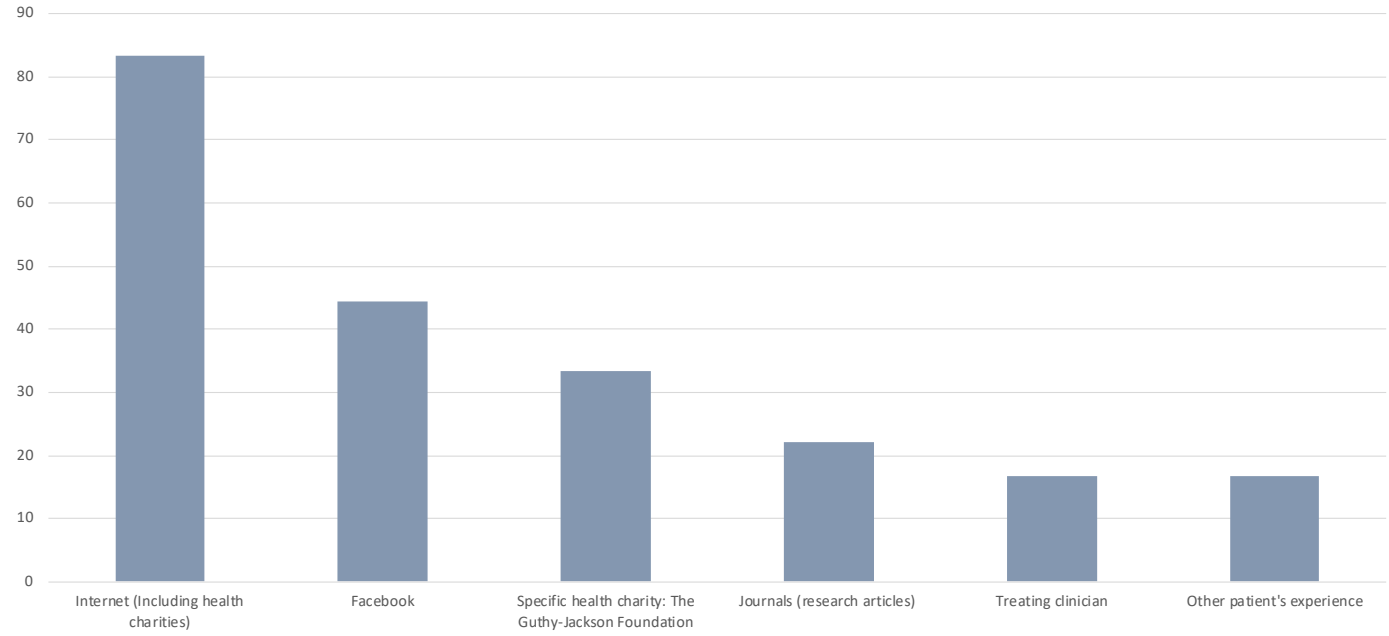

Figure 6.1: Access to information

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by seven participants (38.89%) was other peoples experiences.

Participant describes other people's experiences as helpful (Peer-to-peer)

Knowing that there's somebody else with it was quite good. That was the best thing for me initially. I suppose it was knowing that people don't die from it. Some people have died from it but it's not the predominant type thing. That there is other people that have been in this situation and it was good to speak to them. That there are some things to do for bladder and for bowels and stuff like that, that other people have written about because it had already happened to them. Participant NMO_006

Putting your mind at ease that you're not alone. That's probably been the biggest one, also certain treatments, some treatments work for some people, I know it doesn't work for others it doesn't yes, but it just gives you peace mind where you can go and research and then see what other treatment's been done and what I might be able to suggest to a neurologist and yes, things like that. Participant NMO_009

Usually the other patients. Participant NMO_014

Participant describes talking to their doctor or specialist as helpful

I think the most helpful was, to be honest, probably first would have been my MS specialist and then second was the Australian Facebook Group. Participant NMO_004

I went and saw, actually I did go and see a neurologist in LOCATION METROPOLITAN. The information that he sent back through was the most informative about my condition. Participant NMO_008

Probably the most helpful would be my old neurologist. He was exceptionally good. He would sit down and discuss with me if I have a query or anything that was not right. Participant NMO_013

Participant describes information specific to their condition (and sub-types) as helpful

More management plans. Knowing about the different types of NMO, what are the effects, whether is a one-off thing, whether it's relapsing form and management plan. What sensation will come up and that kind of stuff, yes the symptoms? Residual symptoms, mainly residual symptoms because I need to work out whether is it residual symptoms or is it a relapse or whether I need to go to hospital. Actually, it's that kind of thing that sort of help me. Participant NMO_001

Probably, I just think sometimes NAME DOCTOR puts up webinars explaining in layman's terms how the water channel works and how this works and that. I find that good because you're seeing it and people can ask questions. I guess once you've got the diagnosis, you've got the treatment, and you're fine, there's not much more. Unless there's new research coming out, there's not a lot of changes, I guess. Participant NMO_015

I think it's the one explaining the NMO and what could happen. Participant NMOCA_006

Table 6.3: Information that was helpful

Information that has been helpful	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes other people's experiences as helpful (Peer-to-peer)	7	38.89	3	33.33	4	44.44	2	25.00	5	50.00	5	55.56	2	22.22
Participant describes talking to their doctor or specialist as helpful	4	22.22	2	22.22	2	22.22	2	25.00	2	20.00	3	33.33	1	11.11
Participant describes information specific to their condition (and sub-types) as helpful	3	16.67	3	33.33	0	0.00	2	25.00	1	10.00	1	11.11	2	22.22

Information that has been helpful	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes other people's experiences as helpful (Peer-to-peer)	7	38.89	6	60.00	1	12.50	4	66.67	3	25.00	2	28.57	5	45.45
Participant describes talking to their doctor or specialist as helpful	4	22.22	3	30.00	1	12.50	1	16.67	3	25.00	0	0.00	4	36.36
Participant describes information specific to their condition (and sub-types) as helpful	3	16.67	0	0.00	3	37.50	1	16.67	2	16.67	1	14.29	2	18.18

Information that has been helpful	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 other people's experiences as helpful (Peer-to-peer)	7	38.89	3	37.50	10	38.46	7	70.00	5	31.25	2	100.00	2	66.67	5	33.33
Participant describes talking to their doctor or specialist as helpful	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 information specific to their condition (and sub-types) as helpful	3	16.67	2	25.00	5	19.23	3	30.00	3	18.75	0	0.00	0	0.00	3	20.00

Table 6.4: Information that was helpful (Subgroup variation)

Information that has been helpful	More frequent	Less frequent
Participant describes other people's experiences as helpful (Peer-to-peer)	High to very high fear Moderate to very poor physical function Trade or high school Mid to low socioeconomic status	Low to moderate fear Good to very good physical function University

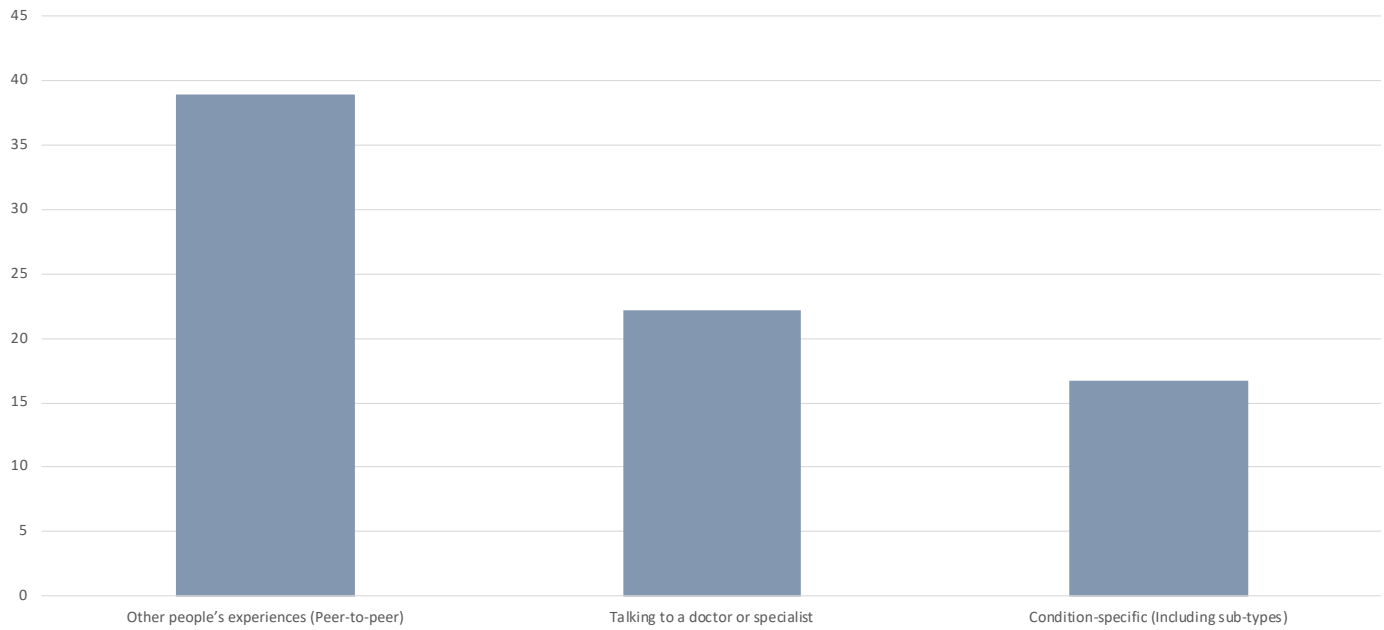

Figure 6.2: Information that was helpful

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common response was that no information was not helpful (n=6, 33.33%)

Participant describes no information being not helpful

No, not really, because a lot of people have different symptoms or different side effects. Some people get it in their spine and so far, touch wood, I've only had it in my eye. Participant NMO _007

No, not really, especially the Facebook page that everything's positive, I think it's run by two nurses on there as the admin and they watch what everyone says, but yes, everything's been good.. Participant NMO_009

No, not really. Participant NMOCA_006

Participant describes feeling confident in deciding if something is not helpful (or not credible)

I've avoided those things. If I found something, especially in the early days, if I found something that was quite negative, then I would not continue reading that because I wasn't going to allow myself to get into a situation of the doom of it because there was no point, because there was no option. I'm that kind of way inclined and online there are some very upsetting situations and when you're early diagnosed, it's good to avoid that. I think that-- I don't know. I think I'm somebody who would-- I take the positives out of just about most of the things I can find rather than the negatives. Participant NMO_006

No, not really. Yes, not really. I think probably with Facebook pages, people put up their stories, their experiences, and ask questions. Maybe, I don't know, I think you need to take what you can from that. Participant NMO_015

I don't think so. As I said, she's selective in what she researches. She's not into populist treatments, if you like, from our alternative people. Participant NMOCA_004

Table 6.5: Information that was not helpful

Information that has not been helpful	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes no information being not helpful	6	33.33	3	33.33	3	33.33	3	37.50	3	30.00	2	22.22	4	44.44
Participant describes feeling confident in deciding if something is not helpful (or not credible)	2	11.11	1	11.11	1	11.11	0	0.00	2	20.00	1	11.11	1	11.11

Information that has not been helpful	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes no information being not helpful	6	33.33	4	40.00	2	25.00	3	50.00	3	25.00	1	14.29	5	45.45
Participant describes feeling confident in deciding if something is not helpful (or not credible)	2	11.11	1	10.00	1	12.50	1	16.67	1	8.33	1	28.57	1	9.09

Information that has not been helpful	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 no information being not helpful	6	33.33	3	37.50	9	34.62	2	20.00	4	25.00	2	100.00	2	66.67	4	26.67
Participant describes feeling confident in deciding if something is not helpful (or not credible)	2	11.11	2	25.00	4	15.38	2	20.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 6.6: Information that was not helpful (Subgroup variations)

Information that has not been helpful	More frequent	Less frequent
Participant describes no information being not helpful	Good to very good physical function Mid to low socioeconomic status Aged 45 or older	Moderate to very poor physical function Aged 18 to 44

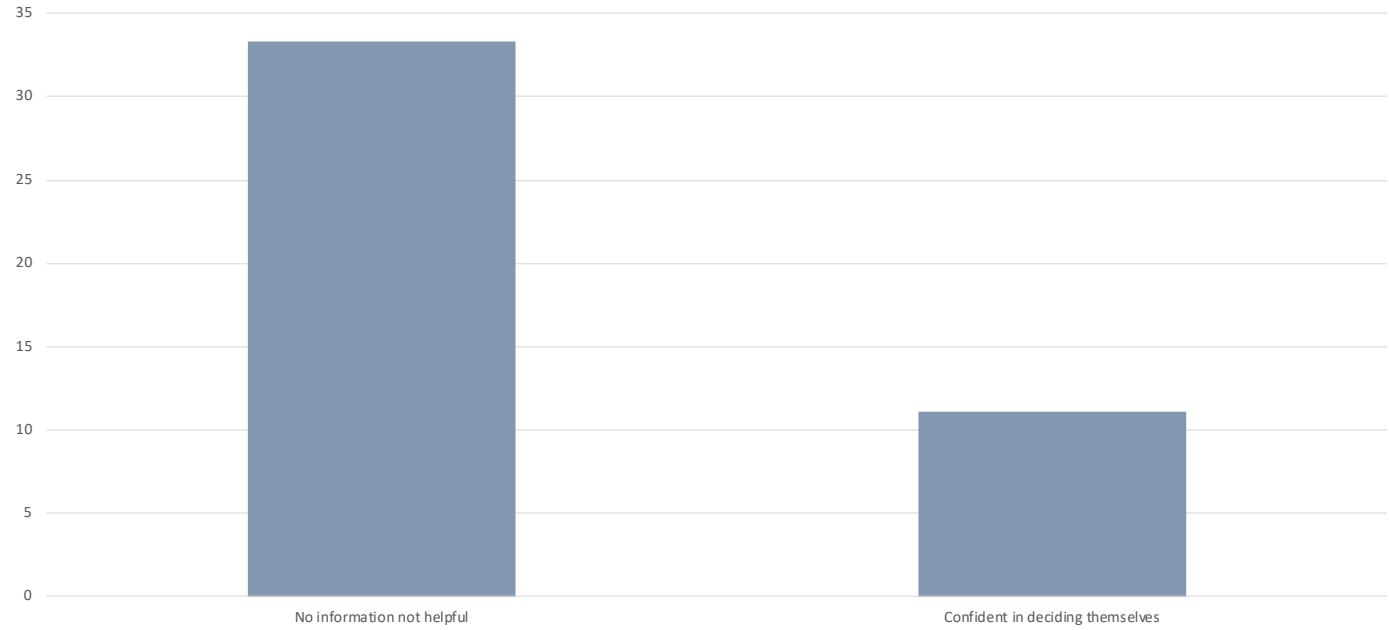

Figure 6.3: Information that was not helpful

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Overall, the most common theme was online information (n=5, 27.78%).

Online information as main preference

I think online is good because you can read it at your leisure. Participant NMO_002

I like to read online because I like to do it in my own time where I can take breaks and stuff if I'm upset by something. I haven't had a lot of good experiences talking to my specialists or doctors about NMO, but I don't really get much information on it. Participant NMO_010

I think online because then I can just read it and ingest it and go back. Participant NMO_015

Talking to someone plus online information as main preference

Okay, online, and talking to someone. Participant NMO_001

Online is brilliant if you can read it and print it out and just have readily access to it. Then to improve on that would beg the ability to contact someone and discuss that with them. Participant NMO_014

I think online is good because you can access it at any time, but I still think human contact and that personal conversations with people is very valuable as well, and especially when it's another person with the disease, not necessarily a medical field. I don't think I would be interested in having my doctors just on phone, I'd rather see them in person. I think there's value in actually reading a person's face and your social cues and things like that. The online information is good especially if you're researching anything, it's good. Participant NMO_017

Talking to someone as main preference

Look, because I'm a peer support volunteer, I think there's nothing better than talking one-on-one with a person that understands because the symptoms are so weird that often, it's only the people that have gone through that, that can really relate. Participant NMO_004

It would be speaking to a neurologist and listening to them, it would be number one, yes. Participant NMO_009

Talking to people I love, actually. Face-to-face when we go to groups, just because of your experience, and what happened to you, and how did this all come about, and what have you done to help with the pain? Have you done this. Participant MOG_006

Table 6.7: Information preferences

Information preferences	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very goo physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Online information as main preference	5	27.78	3	33.33	2	22.22	2	25.00	3	30.00	1	11.11	4	44.44
Talking to someone plus online information as main preference	3	16.67	3	33.33	0	0.00	3	37.50	0	0.00	1	11.11	2	22.22
Talking to someone as main preference	3	16.67	2	22.22	1	11.11	2	25.00	1	10.00	3	33.33	0	0.00

Information preferences	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Online information as main preference	5	27.78	2	20.00	3	37.50	1	16.67	4	33.33	2	28.57	3	27.27
Talking to someone plus online information as main preference	3	16.67	1	10.00	2	25.00	1	16.67	2	16.67	1	28.57	2	18.18
Talking to someone as main preference	3	16.67	2	20.00	1	12.50	2	33.33	1	8.33	0	28.57	3	27.27

Information preferences	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	%
Online information as main preference	5	27.78	4	50.00	9	34.62	4	40.00	5	31.25	0	0.00	0	0.00	5	33.33
Talking to someone plus online information as main preference	3	16.67	3	37.50	6	23.08	1	10.00	3	18.75	0	0.00	0	0.00	3	20.00
Talking to someone as main preference	3	16.67	1	12.50	4	15.38	2	20.00	2	12.50	1	50.00	2	66.67	1	6.67

Table 6.8: Information preferences (Subgroup variations)

Information preferences	More frequent	Less frequent
Online information as main preference	Good to very good physical function	Moderate to very poor physical function Mid to low socioeconomic status

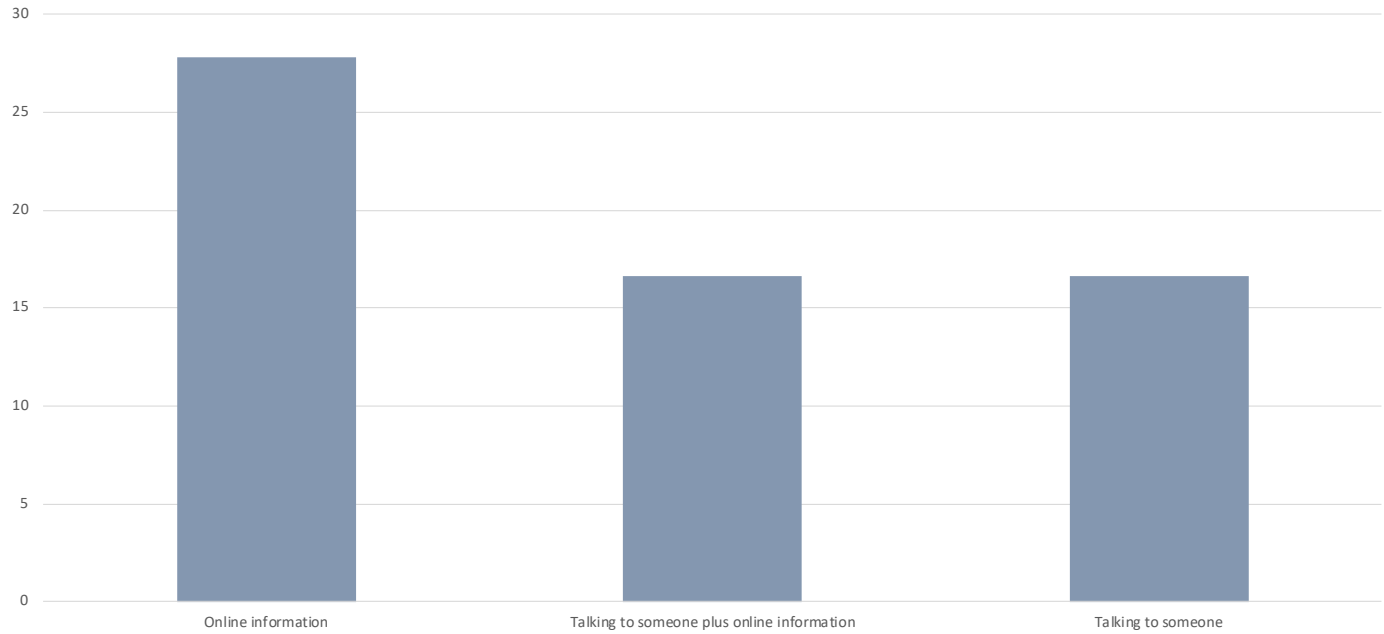

Figure 6.4: Information preferences

Information preferences: Rationale

The most common theme reason for their information preference was due to being able to digest information at their own pace (n=7, 38.89%).

Rational for preference is due to being able to digest information at their own pace

Online even if I can't remember everything, I can save the page so I can read it again whenever I want. Participant NMO_001

I'd probably prefer booklets and stuff like that to read in my own time, just because I'm quite busy. Participant NMO_003

I like to read online because I like to do it in my own time where I can take breaks and stuff if I'm upset by something. Participant NMO_010

Rationale for their preference is that it is more supportive and/or they can share experiences with peers

I think there's nothing better than talking one-on-one with a person that understands because the symptoms are so weird that often, it's only the people that have gone through that, that can really relate. Participant NMO_004

I still think human contact and that personal conversations with people is very valuable as well, and especially when it's another person with the disease, not necessarily a medical field. I don't think I would be interested in having my doctors just on phone, I'd rather see them in person. I think there's value in actually reading a person's face and your social cues and things like that. Participant NMO_017

Talking to people I love, actually. Face-to-face when we go to groups, just because of your experience, and what happened to you, and how did this all come about, and what have you done to help with the pain? Have you done this? Participant MOG_006

Rational for preference is simply a personal preference/no strong rationale

I don't think I have a preference. I probably would do all of them. Participant NMO_006

I think online information is probably the best. As I said, NAME PERSON CARED FOR's on MOG support pages and things like that. I think that's probably what we prefer, as far as the way of doing it. Participant NMOCA_004

Rationale for preference is due to accessibility

Online is brilliant if you can read it and print it out and just have readily access to it. Participant NMO_014

I think online is good because you can access it at any time. Participant NMO_017

The ease of online and then talking to someone just being able ask questions and get reassurance. Participant NMOCA_002

Rationale for their preference is there being a wider range of information available for them to choose from

When it first happened to me, it was a very new thing and not many people knew what was going on. In America, I could get on and redo the research on it type of thing. I would write my questions down and then go to my neurologist. A lot of people, if you say NMO, they'll say, "What's that?" Then I have to tell them what it is. What I'm trying to say is, I have to tell people what I have, what I do, what treatment I have and this is what's happened to me. Participant NMO_013

Table 6.9: Information preferences: Rationale

Rationale for information preference	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Rational for preference is due to being able to digest information at their own pace	7	38.89	3	33.33	4	44.44	4	50.00	3	30.00	2	22.22	5	55.56
Rationale for their preference is that it is more supportive and/or they can share experiences with peers	4	22.22	3	33.33	1	11.11	3	37.50	1	10.00	2	22.22	2	22.22
Rational for preference is simply a personal preference/no strong rationale	3	16.67	1	11.11	2	22.22	0	0.00	3	30.00	3	33.33	0	0.00
Rationale for preference is due to accessibility	2	11.11	2	22.22	0	0.00	2	25.00	0	0.00	0	0.00	2	22.22

Rationale for information preference	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Rational for preference is due to being able to digest information at their own pace	7	38.89	2	20.00	5	62.50	2	33.33	5	41.67	6	85.71	1	9.09
Rationale for their preference is that it is more supportive and/or they can share experiences with peers	4	22.22	1	10.00	3	37.50	1	16.67	3	25.00	1	14.29	3	27.27
Rational for preference is simply a personal preference/no strong rationale	3	16.67	3	30.00	0	0.00	1	16.67	2	16.67	1	14.29	2	18.18
Rationale for preference is due to accessibility	2	11.11	1	10.00	1	12.50	1	16.67	1	8.33	0	0.00	2	18.18

Rationale for information preference	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	%
Rational for preference is due to being able to digest information at their own pace	7	38.89	1	12.50	8	30.77	2	20.00	7	43.75	0	0.00	0	0.00	7	46.67
Rationale for their preference is that it is more supportive and/or they can share experiences with peers	4	22.22	0	0.00	4	15.38	1	10.00	4	25.00	0	0.00	1	33.33	3	20.00
Rational for preference is simply a personal preference/no strong rationale	3	16.67	1	12.50	4	15.38	2	20.00	1	6.25	2	100.00	1	33.33	2	13.33
Rationale for preference is due to accessibility	2	11.11	1	12.50	3	11.54	3	30.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 6.10: Information preferences: Rationale (Subgroup variations)

Rationale for information preference	More frequent	Less frequent
Rational for preference is due to being able to digest information at their own pace	Low to moderate fear Good to very good physical function University Aged 18 to 44	Moderate to very poor physical function Trade or high school Aged 45 or older

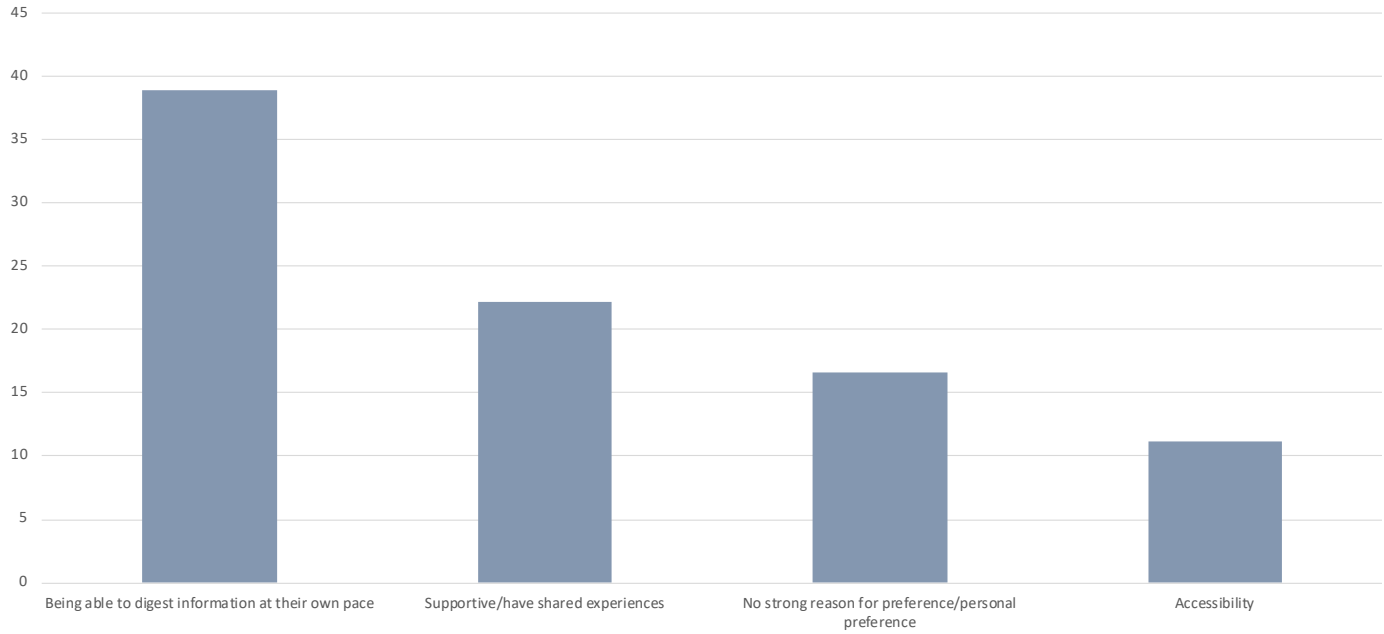

Figure 6.5: Information preferences: Rationale

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common times that participants described being receptive to receiving information was from the beginning (diagnosis) (n=7, 38.89%), and participants describing being receptive to information after a specific amount of time had passed (n=7, 38.89%).

Participant describes being receptive from the beginning (diagnosis)

I think when it was all new, because I had to get a grasp on it. I had to understand what- I think that's the medical side of me coming out- what the body was doing, how it could heal. Participant NMO_017

For me, it was immediately after the diagnosis so when we went to LOCATION METROPOLITAN in April 2019. When I saw the professor told us what is false, as soon as we got home I started researching so that's when I just needed to know and that's how I've worked with everything. Participant NMOCA_003

I think I would have taken information in right at the very outset. The issue was we weren't really given much information. Participant NMOCA_007

Participant describes being receptive to information after a specific amount of time

At the start, it was me looking for things which I felt like I couldn't find, and then probably like halfway through, so probably after a year of being diagnosed, that's when I started to, I guess, take things more in, and think about things, and not be so overwhelmed. Whereas now, I feel like I can be really-- I can try this, this ones not a good idea. I can think about things, thinking through more. Participant NMO_005

When do I feel like? Probably just more recently. Yes, it's probably around six, well, more than six to ten months. I think I needed to come to accepting the diagnosis first before receiving any more information. Participant NMO_001

I suppose four or five months after the diagnosis and after everything had probably slowed down a bit and calmed down 'then' because then I would absolutely read it in a clear mind. Participant MOG_006

Table 6.11: Timing of information

Timing of information	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very goo physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes being receptive from the beginning (diagnosis)	7	38.89	4	44.44	3	33.33	4	50.00	3	30.00	2	22.22	5	55.56
Participant describes being receptive to information after a specific amount of time	7	38.89	3	33.33	4	44.44	3	37.50	4	40.00	5	55.56	2	22.22

Timing of information	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes being receptive from the beginning (diagnosis)	7	38.89	3	30.00	4	50.00	3	50.00	4	33.33	1	14.29	6	54.55
Participant describes being receptive to information after a specific amount of time	7	38.89	5	50.00	2	25.00	2	33.33	5	41.67	3	42.86	4	36.36

Timing of information	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes being receptive from the beginning (diagnosis)	7	38.89	3	37.50	10	38.46	4	40.00	6	37.50	1	50.00	1	33.33	6	40.00
Participant describes being receptive to information after a specific amount of time	7	38.89	2	25.00	9	34.62	3	30.00	6	37.50	1	50.00	2	66.67	5	33.33

Table 6.12: Timing of information

Timing of information	More frequent	Less frequent
Participant describes being receptive from the beginning (diagnosis)	Low to moderate fear Good to very good physical function University Mid to low socioeconomic status Aged 45 or older	Moderate to very poor physical function Aged 18 to 44
Participant describes being receptive to information after a specific amount of time	Moderate to very poor physical function Trade or high school	Good to very good physical function University

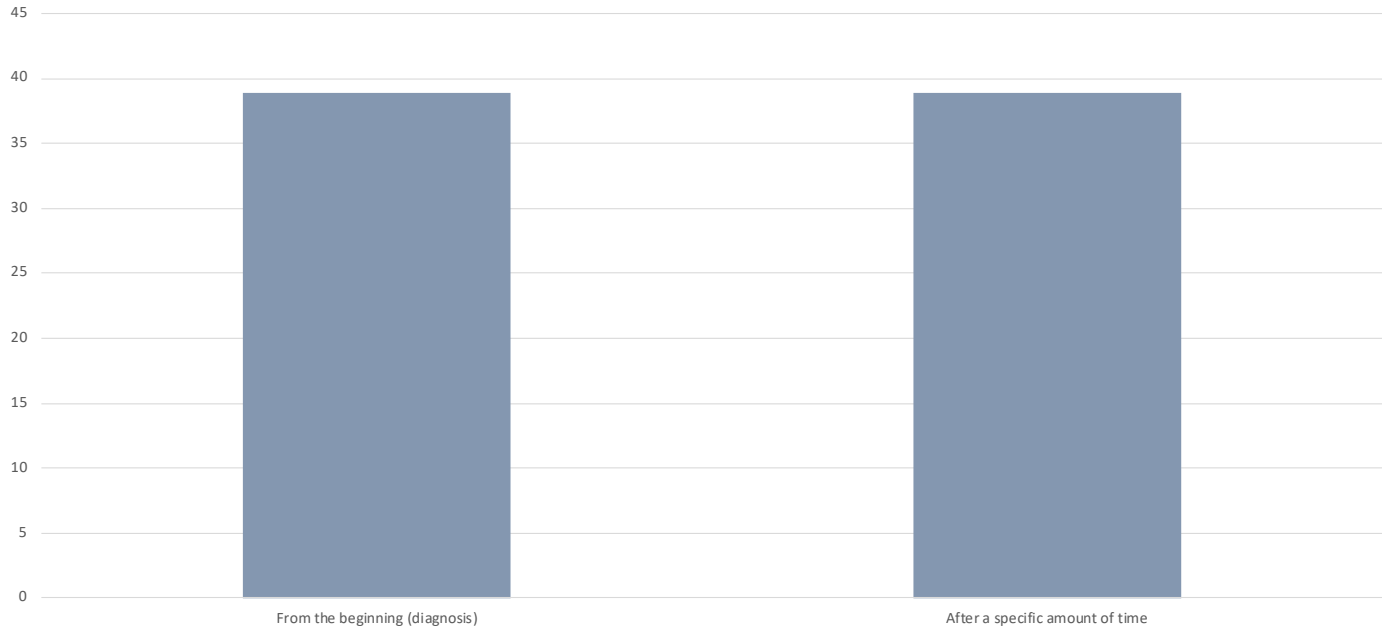

Figure 6.6: Timing of information

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall negative experience (n=11, 61.11%) followed by five participants (27.78%) who described an overall positive experience.

Participant describes an overall negative experience with health professional communication

Very little knowledge out there and lack of discussion more than anything. I felt like saying to my GP, "Have you actually Googled my disease and read anything about it?" Participant NMO_014

Honestly, what I went through-- Well, my first attack of optic neuritis is now leaving me legally blind. I think that there has to be-- The doctors, I just don't trust them anymore, because I trusted

them so much, and I believed what they said, and I honestly kind of blame them for where I am at now because I feel like doctors go through like, "You have this, yes, you don't have this," and because of-- From what I understand, NMO is really rare, they just didn't know what they were talking about. Participant NMO_005

To be frank, not a very good one. I understand specialist are busy people and you need to see other not just us, but we haven't been given any leaflets, no information, no referrals anywhere besides just basically being told, "Okay, this is what you have." Then we've had to search, to collect information ourselves, and I'm happy to obviously do it myself sometimes, particularly at the start, it would be helpful if there was some good example of almost like a booklet or something with for dummies kind of thing, that would answer the 30 questions, I'm obviously worried and want to know is my partner going to die? Where do I find information on what happens? The options, just something basic would be really helpful. Participant NMOCA_003

Participant describes an overall positive experience with health professional communication

Yes, yes. They're fine. Whatever I asked they were able to answer but I think neurologists is all-- Because I didn't do enough research, I didn't know what to ask sometimes. I don't know what I'm supposed to ask. *Participant NMO_001*

In general, they're quite intrigued. If I see a new doctor, they want to know, and they say, "How did you present? What was it like the first time?" I haven't had too bad a journey with it, but mainly, a lack of info. Oh, sorry, the other person I did get to see was the ophthalmologist. I was under the care of an ophthalmologist, I forgot to mention that. It was funny because he was having a lecture the next day on NMO and he asked me to look at his notes [laughs] to see how accurate they were. It's educating the medical community as well. *Participant NMO_004*

It's been all good, all been absolutely positive, a lot of the general practitioner and my local doctor, he does it all day, any of the doctors I've seen, the GP's that they don't seem to know much about it at all. They generally have to look up the condition to find out, but the neurologist have obviously been brilliant and my physio, like I said, who knew nothing about the disease he studied for days about the disease. Participant NMO_009

Participant describes an overall positive experience with health professional communication with the exception of one or two occasions

Very good. I've got no complaints with any times I've been in the hospitals and 99% of doctors have been really good. I've only had one doctor that just had a bad attitude. Participant NMO_007

The neurologists have been helpful. A few of them have been pretty bleak about his prognosis or about the future. So I that hasn't been reassuring. Participant NMOCA_002

Where we are now, definitely it's improved. We've got a good relationship with the neurologist and our GP is a lot more informed now. In the beginning, the GP had absolutely no idea of what the disease was, but she has definitely done a lot of research herself to now find out a lot more about it. Participant NMOCA_007

Table 6.13: Healthcare professional communication

Health professional communication	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes health professional communication as limited in relation to their understanding of the condition	8	44.44	3	33.33	5	55.56	4	50.00	4	40.00	2	22.22	6	66.67
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	5	27.78	4	44.44	1	11.11	3	37.50	2	20.00	4	44.44	1	11.11
Participant describes health professional communication as being dismissive (One way conversation)	4	22.22	1	11.11	3	33.33	2	25.00	2	20.00	1	11.11	3	33.33
Participant describes healthcare communication as limited (they have not had any/a lot)	1	5.56	0	0.00	1	11.11	0	0.00	1	10.00	0	0.00	1	11.11

Health professional communication	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes an overall negative experience with health professional communication	11	61.11	7	70.00	4	50.00	5	83.33	6	50.00	5	71.43	6	54.55
Participant describes an overall positive experience with health professional communication	5	27.78	2	20.00	3	37.50	1	16.67	4	33.33	2	28.57	3	27.27
Participant describes an overall positive experience with health professional communication with the exception of one or two occasions	1	5.56	1	10.00	0	0.00	0	0.00	1	8.33	0	28.57	1	9.09

Health professional communication	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 an overall negative experience with health professional communication	11	61.11	1	12.50	12	46.15	5	50.00	11	68.75	0	0.00	2	66.67	9	60.00
Participant describes an overall positive experience with health professional communication	5	27.78	3	37.50	8	30.77	0	0.00	4	25.00	1	50.00	1	33.33	4	26.67
Participant describes an overall positive experience with health professional communication with the exception of one or two occasions	1	5.56	4	50.00	5	19.23	4	40.00	0	0.00	1	50.00	0	0.00	1	6.67

Table 6.14: Healthcare professional communication (Subgroup variations)

Health professional communication	More frequent	Less frequent
Participant describes an overall negative experience with health professional communication	More relapses Good to very good physical function Mid to low socioeconomic status Aged 18 to 44	Fewer relapses Moderate to very poor physical function University Higher socioeconomic status
Participant describes an overall positive experience with health professional communication	Fewer relapses Moderate to very poor physical function	More relapses Good to very good physical function Mid to low socioeconomic status

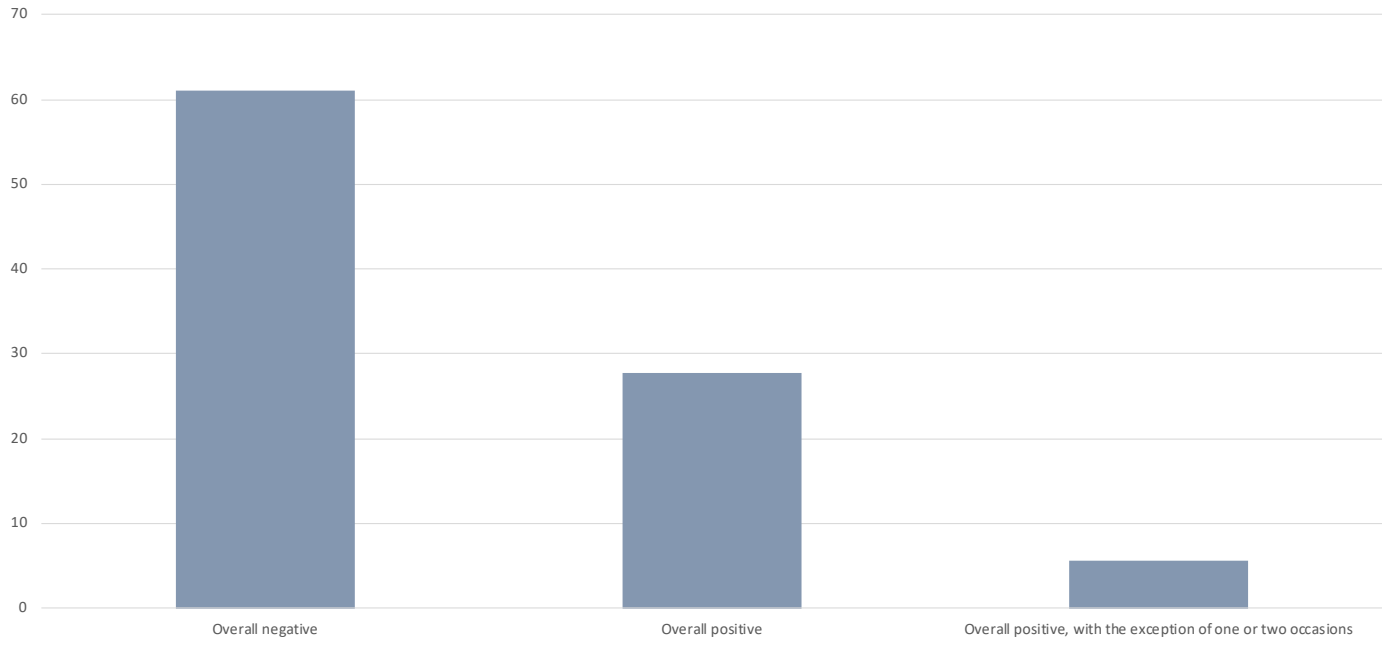

Figure 6.7: Healthcare professional communication

Healthcare professional communication: Reasons for experience

There were eight participants (44.44%) that described health professional communication as limited in relation to their understanding of the condition. Where participants described a positive experience, this related to communication being holistic (two way, supportive and comprehensive conversations) (n=5, 27.78%).

Participant describes health professional communication as limited in relation to their understanding of the condition

I saw my GP six days on the trot every day when my eyesight first went because I just felt there was something really wrong. He was sending me to different people, but he hadn't clue. He'd never heard of it. He was ringing me when I was in hospital to see how I was and apologising. I said, "It's not your fault. You didn't know. It's not something that people necessarily know about, but now I know there's more people out there with it. Now, I think that more people should know about it. Participant NMO_006

Really it hasn't been that great. My GP had to research it herself before she could help me out, but she has been great, don't get me wrong. It would be nice to have someone that understands, be honest, and can give some more idea of what to expect moving forward. Participant NMO_008

It's not been very good. Apart from my neurologist, I've never met a health professional that knew what NMO is, and I've even seen neurologists that hadn't heard of it before. Participant NMO_010

Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)

Being good with my immunologist. It's great to have some in-depth discussions. Participant NMO_002

In general, they're quite intrigued. If I see a new doctor, they want to know, and they say, "How did you present? What was it like the first time?" I haven't had too bad a journey with it, but mainly, a lack of info. Participant NMO_004

It's been all good, all been absolutely positive, a lot of the general practitioner and my local doctor, he does it all day, any of the doctors I've seen, the GP's that they don't seem to know much about it at all. They generally have to look up the condition to find out, but the neurologist have obviously been brilliant and my physio, like I said, who knew nothing about the disease he studied for days about the disease. Participant NMO_009

Participant describes health professional communication as being dismissive (One way conversation)

About my condition in itself, useless. Even the neurologist, yes it's NMO, but it affects your optic nerve and your spinal cord and that's about it and we treat you with this. When I've been back and I'm saying, "Well, I still have bladder problems or I have bowel problems." They go, "Yes, that's part of it." That's what it is. Participant NMO-006

Initially, I was diagnosed with MS, and I was discharged from hospital and ended up three months later in a research clinic, and I would leave the clinic with pathology tests to go and get done, and I'd take a photo of it and go home and Google what I was testing because even if I asked, my neurologist wouldn't explain what he was testing for all. Participant NMO_010

To be frank, not a very good one. I understand specialist are busy people and you need to see other not just us, but we haven't been given any leaflets, no information, no referrals anywhere besides just basically being told, "Okay, this is what you have." Then we've had to search, to collect information ourselves, and I'm happy to obviously do it myself sometimes, particularly at the start, it would be helpful if there was some good example of almost like a booklet or something with for dummies kind of thing, that would answer the 30 questions, I'm obviously worried and want to know is my partner going to die? Where do I find information on what happens? The options, just something basic would be really helpful. Participant NMOCA_003

Participant describes healthcare communication as limited (they have not had any/a lot)

I haven't really been through much. It's kind of just they say, we're sorry to hear that, and that's about it. Participant NMO_003

Yes, pretty good, the neurologist I guess because of the day and age didn't tell me too much, he said you can go and read all about it because he knew I'd be able to and that's about it really. The ophthalmologist didn't really give me too much information and I feel like if their time is short they just give you the diagnosis and that's it. [laughs] Participant MOG_005

Table 6.15: Healthcare professional communication: Reasons for experience

Health professional communication	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes health professional communication as limited in relation to their understanding of the condition	8	44.44	3	33.33	5	55.56	4	50.00	4	40.00	2	22.22	6	66.67
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	5	27.78	4	44.44	1	11.11	3	37.50	2	20.00	4	44.44	1	11.11
Participant describes health professional communication as being dismissive (One way conversation)	4	22.22	1	11.11	3	33.33	2	25.00	2	20.00	1	11.11	3	33.33
Participant describes healthcare communication as limited (they have not had any/a lot)	1	5.56	0	0.00	1	11.11	0	0.00	1	10.00	0	0.00	1	11.11

Health professional communication	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes health professional communication as limited in relation to their understanding of the condition	8	44.44	5	50.00	3	37.50	3	50.00	5	41.67	4	57.14	4	36.36
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	5	27.78	2	20.00	3	37.50	1	16.67	4	33.33	2	28.57	3	27.27
Participant describes health professional communication as being dismissive (One way conversation)	4	22.22	2	20.00	2	25.00	1	16.67	3	25.00	3	42.86	1	9.09
Participant describes healthcare communication as limited (they have not had any/a lot)	1	5.56	1	10.00	0	0.00	0	0.00	1	8.33	1	0.00	0	0.00

Health professional communication	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 health professional communication as limited in relation to their understanding of the condition	8	44.44	0	0.00	8	30.77	4	40.00	8	50.00	0	0.00	1	33.33	7	46.67
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	5	27.78	2	25.00	7	26.92	1	10.00	4	25.00	1	50.00	1	33.33	4	26.67
Participant describes health professional communication as being dismissive (One way conversation)	4	22.22	0	0.00	4	15.38	2	20.00	4	25.00	0	0.00	1	33.33	3	20.00
Participant describes healthcare communication as limited (they have not had any/a lot)	1	5.56	2	25.00	3	11.54	2	20.00	1	6.25	0	0.00	0	0.00	1	6.67

Table 6.16: Healthcare professional communication: Reasons for experience

Health professional communication	More frequent	Less frequent
Participant describes health professional communication as limited in relation to their understanding of the condition	More relapses Good to very good physical function Aged 18 to 44	Fewer relapses Moderate to very poor physical function
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	Fewer relapses Moderate to very poor physical function	More relapses Good to very good physical function Mid to low socioeconomic status

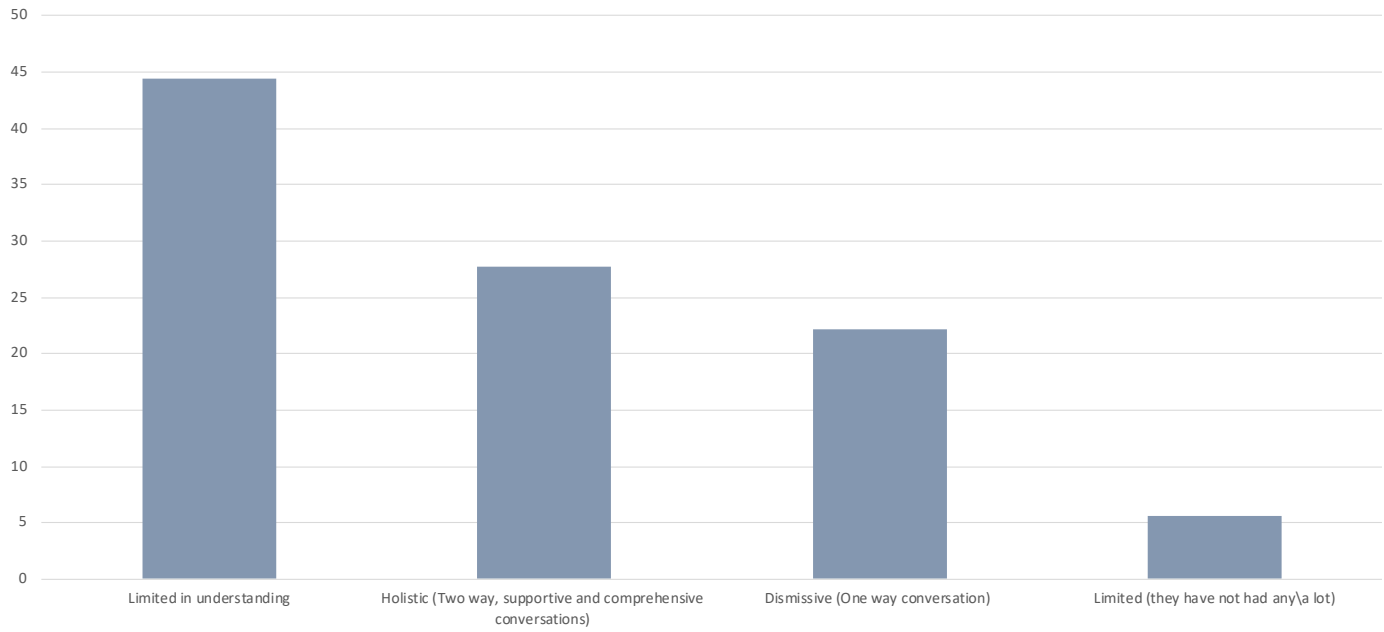

Figure 6.8: Healthcare professional communication: Reasons for experience

Partners in health

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, four scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 6.7.

Overall, the participants in this PEEK study had an average score for **Partners in health: adherence to treatment** (mean = 12.89, SD = 2.68), in the highest quintile indicating excellent adherence to treatment.

Overall, the participants in this PEEK study had an average score for **Partners in health: knowledge** (mean = 23.00, SD = 5.39), **Partners in health: recognition and management of symptoms** (mean = 17.72, SD = 4.07), and **Partners in health: total score** (mean = 65.11, SD = 13.87) in the second highest quintile indicating good knowledge, recognition and, and overall knowledge and confidence for managing their own health.

The average score for **Partners in health: coping** (mean = 11.50, SD = 5.94), was in the middle of the scale, indicating moderate coping.

Comparisons of Partners in health have been made based on **participant type** (Tables 6.18 to 6.19, Figures 6.9 to 6.13), **relapse** (Tables 6.20 to 6.21, Figures 6.14 to 6.18), **fear of progression** (Tables 6.22 to 6.23, Figures 6.19 to 6.23), **physical function** (Tables 6.24 to 6.25, Figures 6.24 to 6.28), **education** (Table 6.26, Figures 6.29 to 6.33), **socioeconomic advantage** (Tables 6.27 to 6.28, Figures 6.34 to 6.38), **age** (Table 6.29, Figures 6.39 to 6.43), **gender,** (Table 6.30), and **location** (Table 6.31).

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a moderate ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had excellent recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had good overall knowledge, coping and confidence for managing their own health.

Table 6.17: Partners in health summary statistics

Partners in health scale (n=18)	Mean	SD	Median	IQR	Possible range	Quintile
Partners in health: knowledge*	23.00	5.39	22.00	4.75	0 to 32	4
Partners in health: coping*	11.50	5.94	11.50	5.50	0 to 24	3
Partners in health: recognition and management of symptoms*	17.72	4.07	19.00	4.00	0 to 24	4
Partners in health: adherence to treatment*	12.89	2.68	12.50	4.50	0 to 16	5
Partners in health: total score*	65.11	13.87	62.50	17.75	0 to 96	4

*Normal distribution use mean and SD as measure of central tendency

Comparisons of Partners in health scales by participant type

Participant type were grouped according to diagnosis of NMOSD, MOG, and family and carers; the NMOSD group includes participants who had

a NMOSD diagnosis, (n=18, 50.00%), participants who had a MOG diagnosis were included in the MOG group (n=8, 22.22%), participants in the NMOSD or MOG groups were included in the NMOSD and MOG subgroup (n=26, 72.22), and family members or carers of people with NMOSD or MOG were included in the Family and carers subgroup (n=10, 27.78%).

Boxplots of each Partners in health scale by **participant type** are displayed in Figures 6.9 to 6.13, summary statistics are displayed in Tables 6.18 and 6.19.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 6.18).

When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.19).

No significant differences were observed between participants by **participant type** for any of the Partners in health scales.

Table 6.18: Partners in health by participant type ANOVA test

Partners in health scale	Group	Number (n=36)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Knowledge	*NMOSD*	18	50.00	23.00	5.39	Between groups	104.00	3.00	34.67	1.34	0.2710
	MOG	8	22.22	26.50	3.07	Within groups	1504.00	58.00	25.93		
	NMOSD and MOG	26	72.22	24.08	5.01	Total	1608.00	61.00			
	Family and carers	10	27.78	22.00	5.93						
Coping	*NMOSD*	18	50.00	11.50	5.94	Between groups	216.80	3.00	72.26	2.61	0.0600
	MOG	8	22.22	14.38	2.97	Within groups	1605.40	58.00	27.68		
	NMOSD and MOG	26	72.22	12.38	5.32	Total	1822.20	61.00			
	Family and carers	10	27.78	16.90	5.11						
Recognition and management of symptoms	*NMOSD*	18	50.00	17.72	4.07	Between groups	46.70	3.00	15.58	1.16	0.3350
	MOG	8	22.22	19.88	1.73	Within groups	782.20	58.00	13.49		
	NMOSD and MOG	26	72.22	18.38	3.62	Total	828.90	61.00			
	Family and carers	10	27.78	16.80	4.10						
Total score	*NMOSD*	18	50.00	65.11	13.87	Between groups	648.00	3.00	216.00	1.33	0.2730
	MOG	8	22.22	75.75	4.98	Within groups	9411.00	58.00	162.30		
	NMOSD and MOG	26	72.22	68.38	12.76	Total	10059.00	61.00			
	Family and carers	10	27.78	66.80	14.52						

Table 6.19: Partners in health by participant type Kruskal-Wallis test

Partners in health scale	Group	Number (n=36)	Percent	Median	IQR	C^2	dF	p-value
adherence to treatment	*NMOSD*	18	50.00	12.50	4.50	4.35	3	0.2260
	MOG	8	22.22	15.00	2.00			
	NMOSD and MOG	26	72.22	14.00	4.00			
	Family and carers	10	27.78	13.50	8.25			

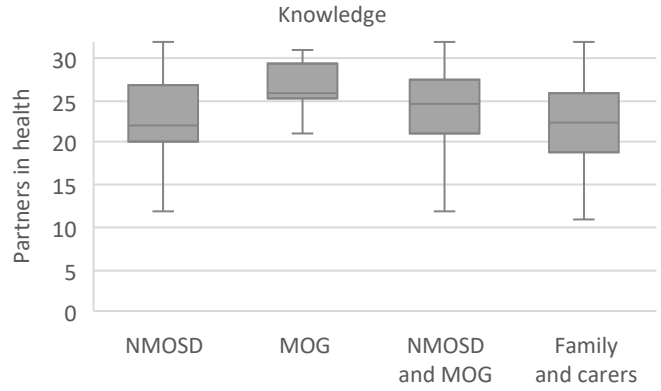

Figure 6.9: Boxplot of Partners in health: knowledge by participant type

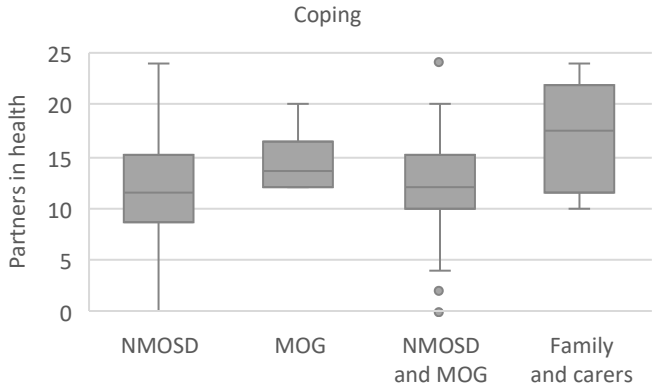

Figure 6.10: Boxplot of Partners in health: coping by participant type

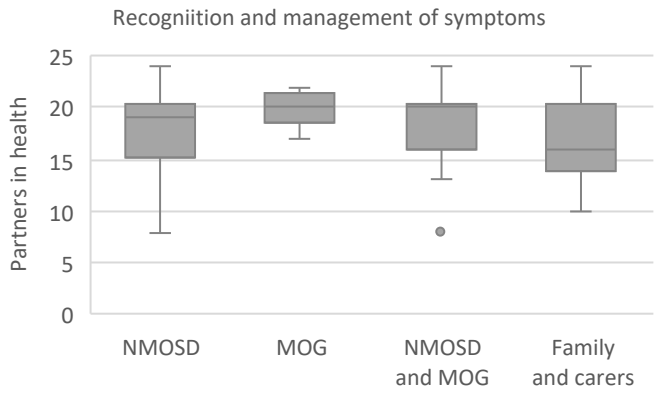

Figure 6.11: Boxplot of Partners in health: recognition and management of symptoms by participant type

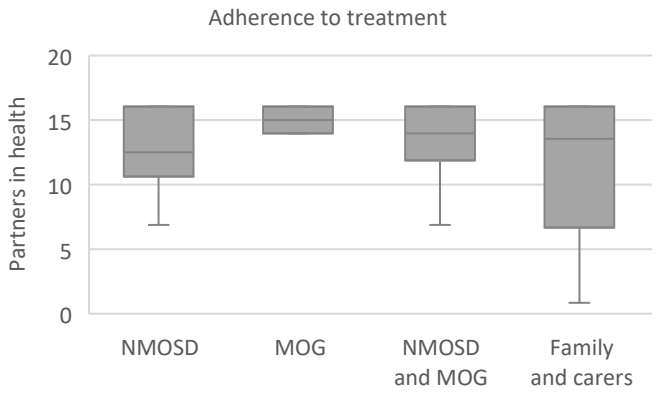

Figure 6.12: Boxplot of Partners in health: adherence to treatment by participant type

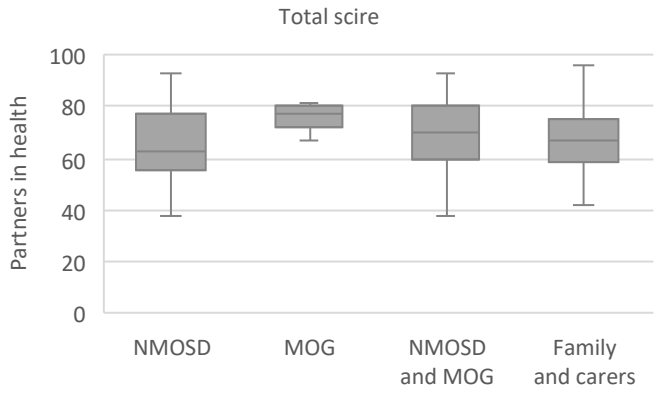

Figure 6.13: Boxplot of Partners in health Total score by participant type

Comparisons of Partners in health scales by relapse

Comparisons were made by NMOSD relapses, those less than two relapses were included in the *fewer relapses* subgroup (n=9, 50.00%), and those that had three or more relapses, in the *more relapses* subgroup (n=9, 50.00%). Only participants with NMOSD were included in this comparison.

Boxplots of each Partners in health scale by **relapse** are displayed in Figures 6.14 to 6.18, summary statistics are displayed in Tables 6.20 to 6.21. A two-sample t-test was used when assumptions for normality and variance were met (Table 6.20), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.21).

No significant differences were observed between participants in the subgroup *fewer relapses* compared to those in the subgroup lived in *more relapses* for any of the Partners in health scales.

Table 6.20: Partners in health by relapse summary statistics and two sample t-test

Partners in health scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Knowledge	*Fewer relapses*	9	50.00	23.78	4.60	0.60	16	0.5566
	More relapses	9	50.00	22.22	6.26			
Coping	*Fewer relapses*	9	50.00	11.22	6.63	-0.19	16	0.8497
	More relapses	9	50.00	11.78	5.56			
Total score	*Fewer relapses*	9	50.00	67.11	15.24	0.60	16	0.5568
	More relapses	9	50.00	63.11	12.94			

Table 6.21: Partners in health by relapse summary statistics and Wilcoxon rank sum tests with continuity correction

Partners in health scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Recognition and management of symptoms	*Fewer relapses*	9	50.00	20.00	2.00	58.50	0.1184
	More relapses	9	50.00	16.00	6.00		
Adherence to treatment	*Fewer relapses*	9	50.00	14.00	6.00	44.00	0.7873
	More relapses	9	50.00	12.00	2.00		

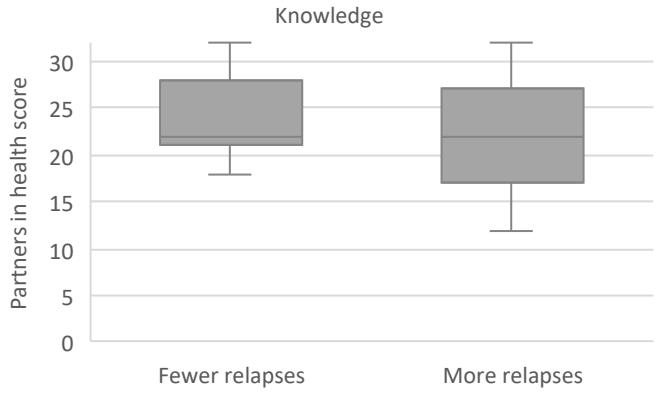

Figure 6.14: Boxplot of Partners in health: knowledge by relapse

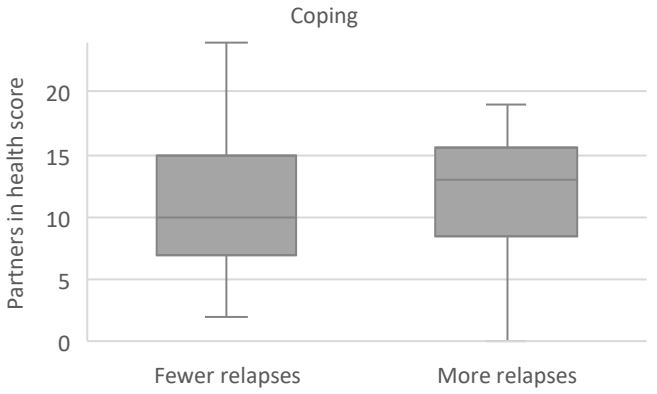

Figure 6.15: Boxplot of Partners in health: coping by relapse

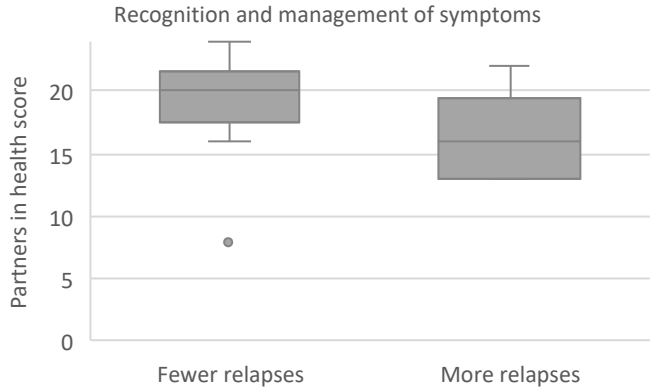

Figure 6.16: Boxplot of Partners in health: recognition and management of symptoms by relapse

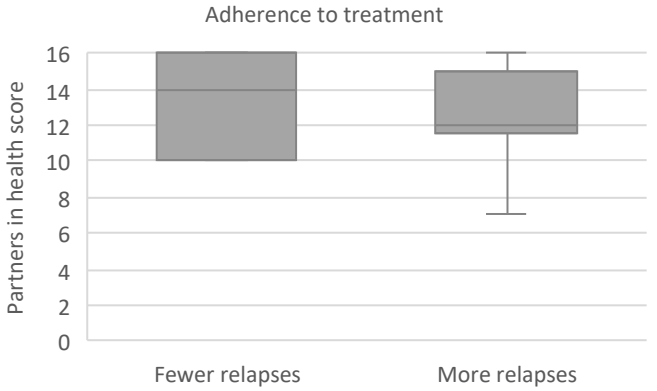

Figure 6.17: Boxplot of Partners in health: adherence to treatment by relapse

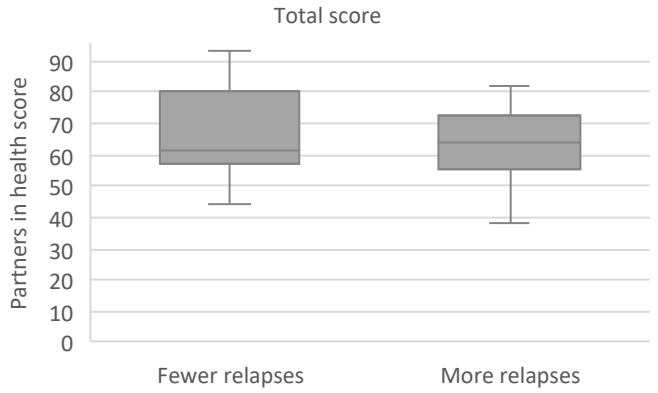

Figure 6.18: Boxplot of Partners in health Total score by relapse

Comparisons of Partners in health scales by fear of progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Participants that scored over 41 in the Fear of progression questionnaire were included in the *High to very high fear* subgroup (n=10, 55.56%), and those that scored less than 41 were included in the *Low to moderate fear* subgroup (n=8, 44.44%). Only participants with NMOSD were included in this comparison.

Boxplots of each Partners in health scale by **fear of progression** are displayed in Figures 6.19 to 6.23, summary statistics are displayed in Tables 6.22 to 6.23. A two-sample t-test was used when assumptions for normality and variance were met (Table 6.22), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.23).

A two sample t-test indicated that the mean score for the **Partners in health total score** [t(16) = 2.20, p=0.0428] was significantly higher for participants in the *Low to moderate fear* subgroup (Mean = 72.38, SD = 11.88) compared to participants in the subgroup *High to very high fear* (Mean = 59.30, SD = 13.00).

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the *Low to moderate fear* subgroup scored lower than participants in the *High to very high fear* subgroup. However, all participants scored in the same range, this indicates that participants had very good overall knowledge, coping and confidence for managing their own health.

Table 6.22: Partners in health by fear of progression summary statistics and two sample t-test

Partners in health scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Knowledge	*Low to moderate fear*	8	44.44	24.88	3.31	1.35	16	0.1953
	High to very high fear	10	55.56	21.50	6.38			
Coping	*Low to moderate fear*	8	44.44	14.50	5.42	2.10	16	0.0521
	High to very high fear	10	55.56	9.10	5.43			
Recognition and management of symptoms	*Low to moderate fear*	8	44.44	19.25	3.81	1.47	16	0.1603
	High to very high fear	10	55.56	16.50	4.03			
Total score	*Low to moderate fear*	8	44.44	72.38	11.88	2.20	16	0.0428*
	High to very high fear	10	55.56	59.30	13.00			

*Significant at p<0.05

Table 6.23: Partners in health by fear of progression summary statistics and Wilcoxon rank sum tests with continuity correction

Partners in health scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Adherence to treatment	*Low to moderate fear*	8	44.44	14.50	3.75	52.50	0.2775
	High to very high fear	10	55.56	12.00	2.25		

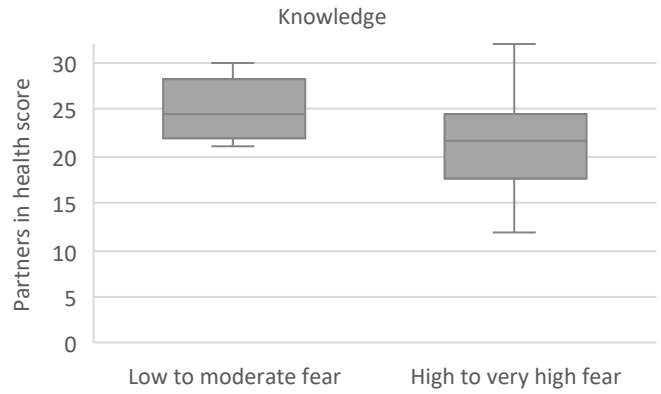

Figure 6.19: Boxplot of Partners in health: knowledge by fear of progression

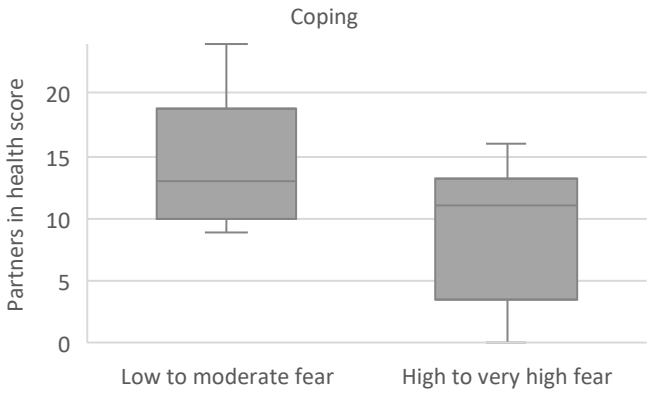

Figure 6.20: Boxplot of Partners in health: coping by fear of progression

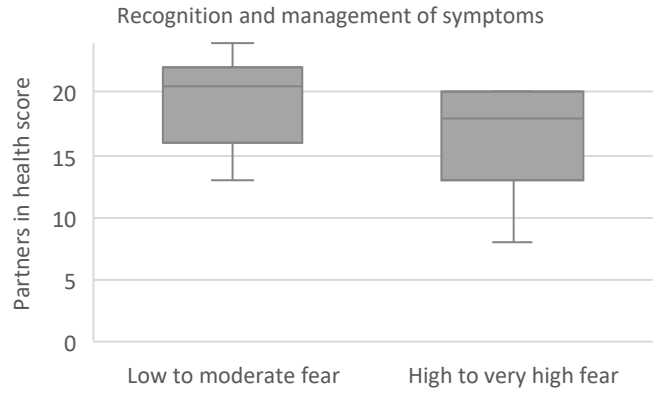

Figure 6.21: Boxplot of Partners in health: recognition and management of symptoms by fear of progression

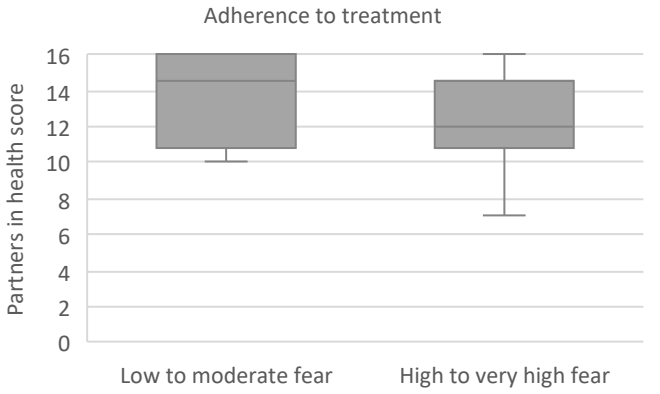

Figure 6.22: Boxplot of Partners in health: adherence to treatment by fear of progression

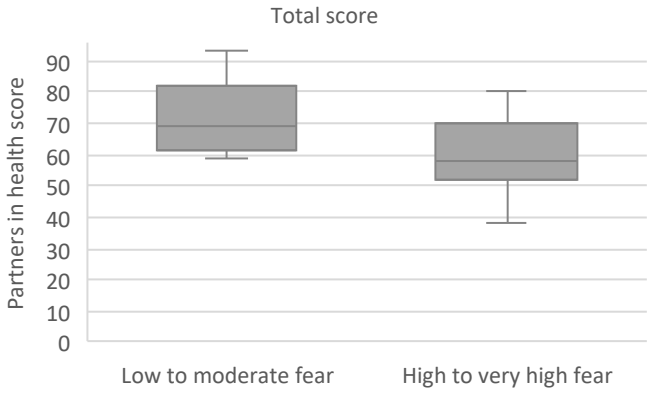

Figure 6.23: Boxplot of Partners in health Total score by fear of progression

Comparisons of Partners in health scales by physical function

The SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. Comparisons were made by **physical function**, participants that scored in the lowest three quintiles of the SF36 Physical functioning scale were included in the *Moderate to very poor physical function* subgroup (n=9, 50.00%), and participants that scored in the highest two quintiles were included in the *Good to very good physical function* subgroup (n=9, 50.00%). Only participants with NMOSD were included in this comparison.

Boxplots of each Partners in health scale by **physical** are displayed in Figures 6.24 to 6.28, summary statistics are displayed in Tables 6.24 to 6.25. A two-sample t-test was used when assumptions for normality and variance were met (Table 6.24), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.25).

No significant differences were observed between participants in the *Moderate to very poor physical function* subgroup compared to those in the *Good to very good physical function* subgroup for any of the Partners in health scales.

Table 6.24: Partners in health by physical function summary statistics and two sample t-test

Partners in health scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Knowledge	*Moderate to very poor physical function*	9	50.00	24.56	5.55	1.24	16	0.2315
	Good to very good physical function	9	50.00	21.44	5.05			
Recognition and management of symptoms	*Moderate to very poor physical function*	9	50.00	17.89	4.88	0.17	16	0.8681
	Good to very good physical function	9	50.00	17.56	3.36			
Adherence to treatment	*Moderate to very poor physical function*	9	50.00	13.44	3.00	0.88	16	0.3948
	Good to very good physical function	9	50.00	12.33	2.35			

Table 6.25: Partners in health by physical function summary statistics and Wilcoxon rank sum tests with continuity correction

Partners in health scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Coping	*Moderate to very poor physical function*	9	50.00	9.00	8.00	20.5	0.08428
	Good to very good physical function	9	50.00	13.00	4.00		
Total score	*Moderate to very poor physical function*	9	50.00	68.00	21.00	42.5	0.8945
	Good to very good physical function	9	50.00	61.00	10.00		

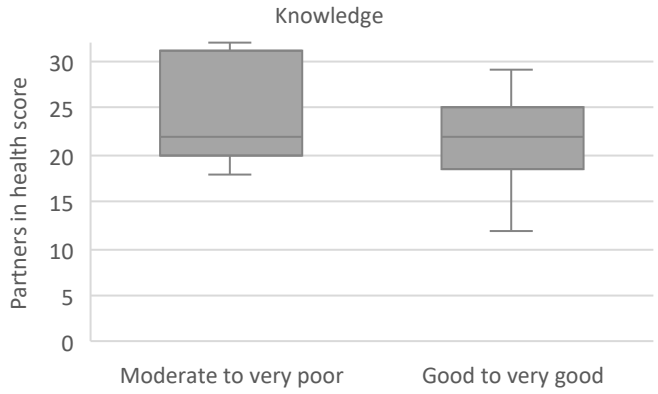

Figure 6.24: Boxplot of Partners in health: knowledge by physical function

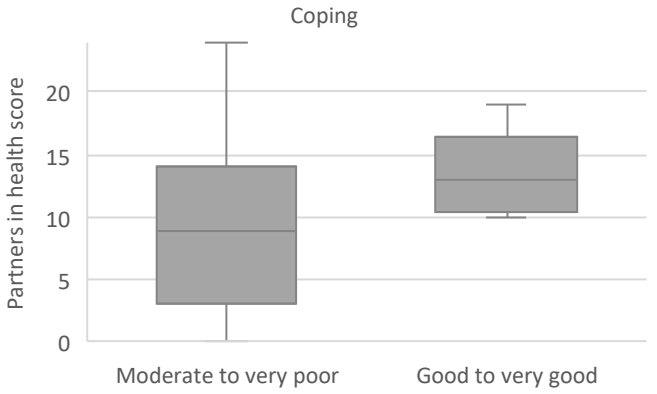

Figure 6.25: Boxplot of Partners in health: coping by physical function

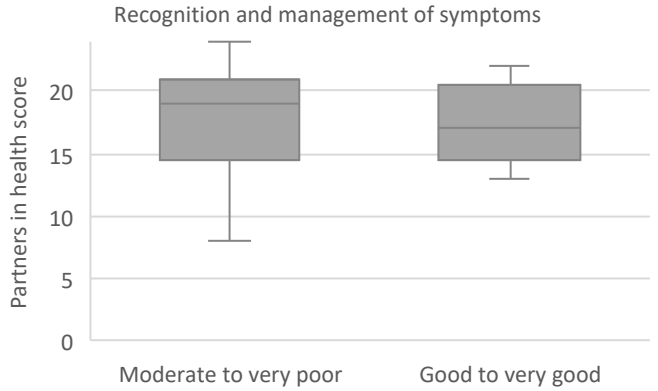

Figure 6.26: Boxplot of Partners in health: recognition and management of symptoms by physical function

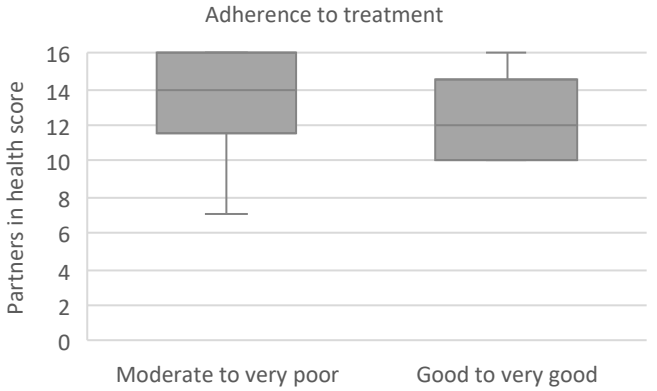

Figure 6.27: Boxplot of Partners in health: adherence to treatment by physical function

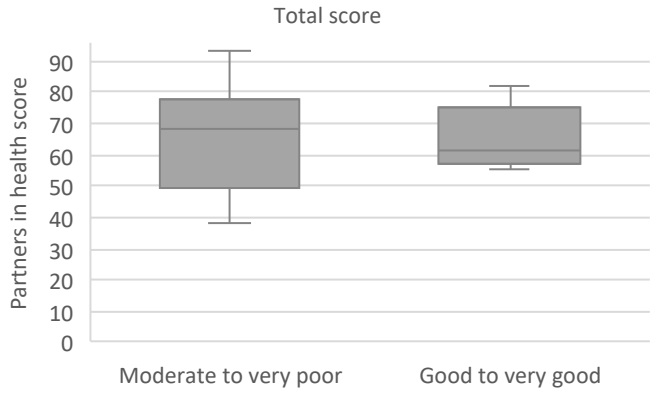

Figure 6.28: Boxplot of Partners in health Total score by physical function

Comparisons of Partners in health scales by education

Comparisons were made by Education status, between those with trade or high school qualifications, trade or high school (n=10, 55.56%), and those with a university qualification, University (n= 8, 44.44%). Only participants with NMOSD were included in this comparison.

Boxplots of each Partners in health scale by **education** are displayed in Figures 6.29 to 6.33, summary statistics are displayed in Table 6.26. Assumptions for normality and variance were met, a two-sample t-test was used (Table 6.26).

A two sample t-test indicated that the mean score for the **Partners in health: recognition and management of symptoms** [t(16) = -2.59, p= 0.0198] was significantly higher for participants in the *University* subgroup (mean = 20.13, SD = 3.27) compared to participants in the *Trade or high school* subgroup (mean = 15.80, SD = 3.71).

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average, participants in the *University* subgroup scored higher than participants in the *Trade or high school* subgroup. This indicates that participants in the *University* subgroup, had excellent recognition and management of symptoms, compared to very good recognition and management of symptoms for participants in the *Trade or high school* subgroup.

Table 6.26: Partners in health by education summary statistics and two sample t-test

Partners in health scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Knowledge	*Trade or high school*	10	55.56	21.90	6.47	-0.97	16	0.3484
	University	8	44.44	24.38	3.58			
Coping	*Trade or high school*	10	55.56	9.90	4.84	-1.30	16	0.2110
	University	8	44.44	13.50	6.89			
Recognition and management of symptoms	*Trade or high school*	10	55.56	15.80	3.71	-2.59	16	0.0198*
	University	8	44.44	20.13	3.27			
Adherence to treatment	*Trade or high school*	10	55.56	12.40	2.76	-0.86	16	0.4026
	University	8	44.44	13.50	2.62			
Total score	*Trade or high school*	10	55.56	60.00	12.99	-1.87	16	0.0795
	University	8	44.44	71.50	12.90			

*Significant at p<0.05

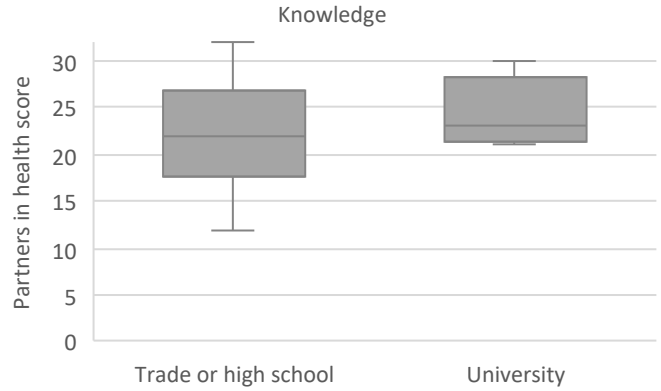

Figure 6.29: Boxplot of Partners in health: knowledge by education

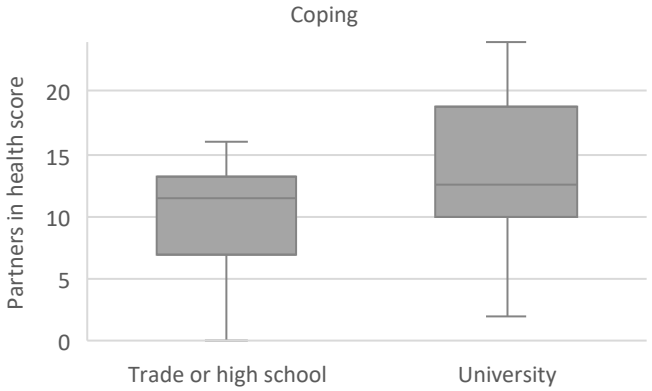

Figure 6.30: Boxplot of Partners in health: coping by education

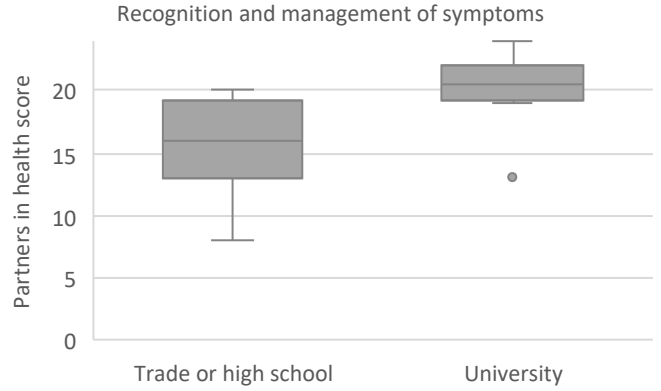

Figure 6.31: Boxplot of Partners in health: recognition and management of symptoms by education

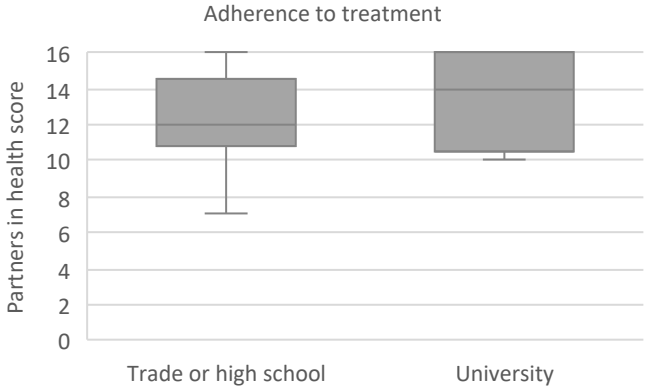

Figure 6.32: Boxplot of Partners in health: adherence to treatment by education

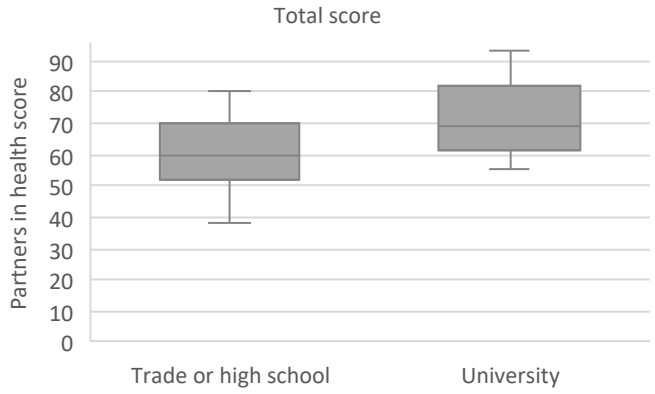

Figure 6.33: Boxplot of Partners in health Total score by education

Comparisons of Partners in health scales by socioeconomic advantage

Comparisons were made by socioeconomic advantage, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, *Mid to low status* (n=6, 33.33%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n=12, 66.67%) . Only participants with NMOSD were included in this comparison.

Boxplots of each Partners in health scale by **socioeconomic advantage** are displayed in Figures 6.34 to 6.38, summary statistics are displayed in Tables 6.27 to 6.28. A two-sample t-test was used when assumptions for normality and variance were met (Table 6.27), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.28).

A two sample t-test indicated that the mean score for the **Partners in health: coping** [t(16) = -2.13, p=0.0494] was significantly higher for participants in the *Higher status* subgroup (Mean = 13.42, SD = 5.71) compared to participants in the *Mid to low status* subgroup (Mean = 7.67, SD = 4.68)

A two sample t-test indicated that the mean score for the **Partners in health: recognition and management of symptoms** [t(16) = -2.41, p=0.0282] was significantly higher for participants in the *Higher status* subgroup (Mean = 19.17, SD = 3.38) compared to participants in the*Mid to low status* subgroup (Mean = 14.83, SD = 4.02).

A two sample t-test indicated that the mean score for the **Partners in health: total score** [t(16) = -3.00, p=0.0084] was significantly higher for participants in the *Higher status* subgroup (Mean = 70.83, SD = 11.90) compared to participants in the *Mid to low status* subgroup (Mean = 53.67, SD = 10.33)

Recognition and management of symptoms

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in the *Higher status* subgroup scored higher than participants in the *Mid to low status* subgroup. This indicates that participants in the *Higher status* subgroup, had a moderate ability to manage the effects of their health condition, compared to a poor ability to manage for participants in the *Mid to low status* subgroup.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average, participants in the *Higher status* subgroup scored higher than participants in the *Mid to low status* subgroup. However, all participants scored in the same range, this indicates that participants had very good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the *Higher status* subgroup scored higher than participants in the *Mid to low status* subgroup. This indicates that participants in the *Higher status* subgroup, had very good overall knowledge, coping and confidence for managing their own health, compared to moderate overall knowledge, coping and confidence for participants in the *Mid to low status* subgroup.

Table 6.27: Partners in health by socioeconomic advantage summary statistics and two sample t-test

Partners in health scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Knowledge	*Mid to low status*	6	33.33	20.00	3.29	-1.77	16	0.0955
	Higher status	12	66.67	24.50	5.71			
Coping	*Mid to low status*	6	33.33	7.67	4.68	-2.13	16	0.0494*
	Higher status	12	66.67	13.42	5.71			
Recognition and management of symptoms	*Mid to low status*	6	33.33	14.83	4.02	-2.41	16	0.0282*
	Higher status	12	66.67	19.17	3.38			
Total score	*Mid to low status*	6	33.33	53.67	10.33	-3.00	16	0.0084*
	Higher status	12	66.67	70.83	11.90			

*Significant at p<0.05

Table 6.28: Partners in health by socioeconomic advantage summary statistics and Wilcoxon rank sum tests with continuity correction

Partners in health scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Adherence to treatment	*Mid to low status*	6	33.33	11.00	3.50	16.50	0.0699
	Higher status	12	66.67	14.00	4.00		

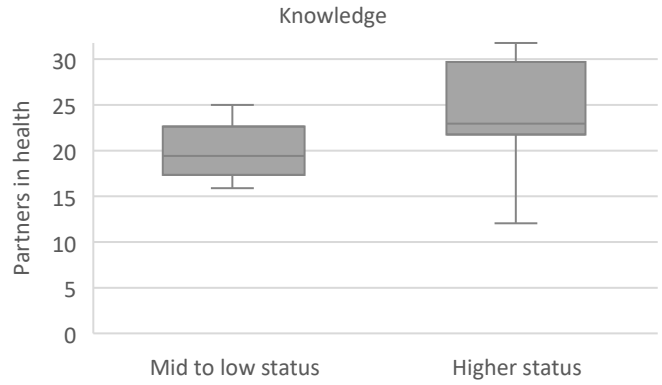

Figure 6.34: Boxplot of Partners in health: knowledge by socioeconomic advantage

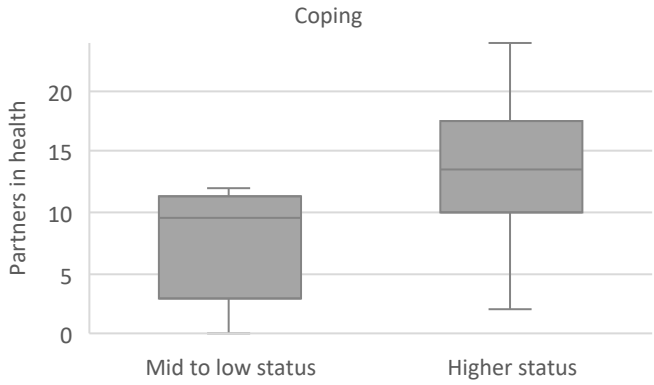

Figure 6.35: Boxplot of Partners in health: coping by socioeconomic advantage

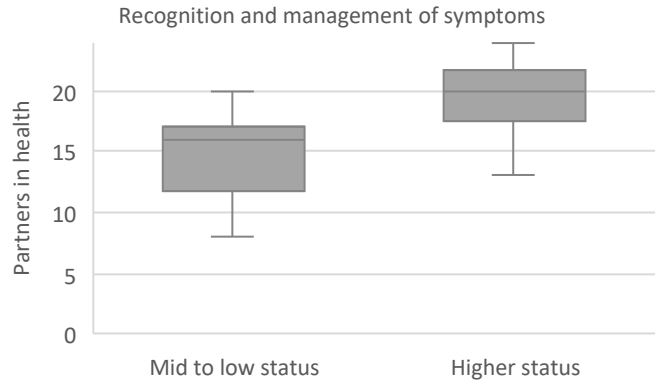

Figure 6.36: Boxplot of Partners in health: recognition and management of symptoms by socioeconomic advantage

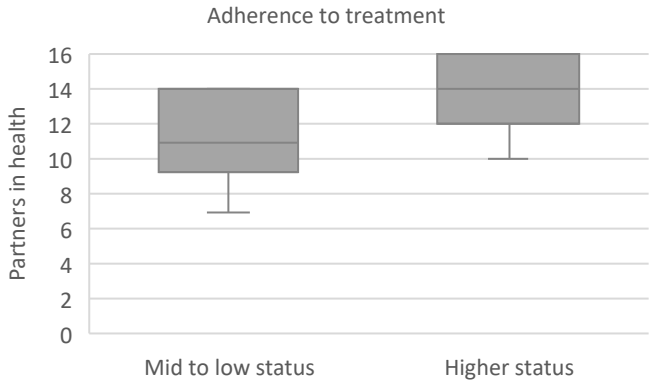

Figure 6.37: Boxplot of Partners in health: adherence to treatment by socioeconomic advantage

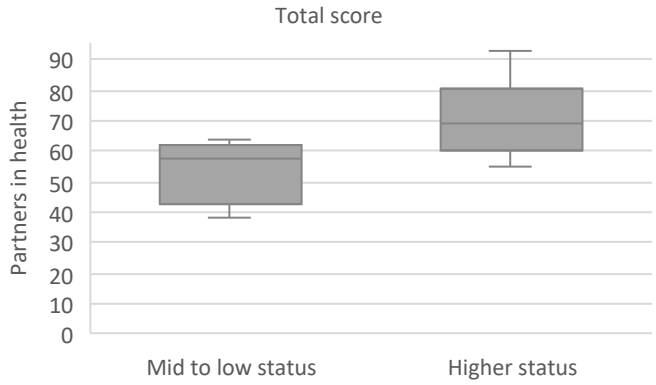

Figure 6.38: Boxplot of Partners in health Total score by socioeconomic advantage

Comparisons of Partners in health scales by age

Participants were grouped according to **age,** with comparisons made between participants *Aged 18 to 44* (n=7, 38.89%), , and *Aged 45 or older* (n=11, 61.11%). Only participants with NMOSD were included in this comparison.

Boxplots of each Partners in health scale by **age** are displayed in Figures 6.39 to 6.43, summary statistics are displayed in Table 6.29. Assumptions for normality and variance were met, a two-sample t-test was used (Table 6.29).

No significant differences were observed between participants in the *Aged 18 to 44* subgroup compared to those in the *Aged 45 or older* for any of the partners in health scales.

Table 6.29: Partners in health by age summary statistics and two sample t-test

Partners in health scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Knowledge	*Aged 18 to 44*	7	38.89	21.14	5.24	-1.18	16	0.2555
	Aged 45 or older	11	61.11	24.18	5.38			
Coping	*Aged 18 to 44*	7	38.89	10.00	6.90	-0.85	16	0.4095
	Aged 45 or older	11	61.11	12.45	5.37			
Recognition and management of symptoms	*Aged 18 to 44*	7	38.89	18.00	3.83	0.22	16	0.8253
	Aged 45 or older	11	61.11	17.55	4.39			
Adherence to treatment	*Aged 18 to 44*	7	38.89	12.29	3.20	-0.75	16	0.4624
	Aged 45 or older	11	61.11	13.27	2.37			
Total score	*Aged 18 to 44*	7	38.89	61.43	14.06	-0.89	16	0.3849
	Aged 45 or older	11	61.11	67.45	13.89			

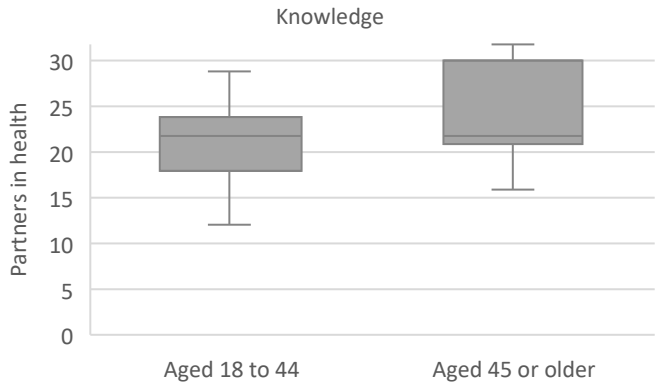

Figure 6.39: Boxplot of Partners in health: knowledge by age

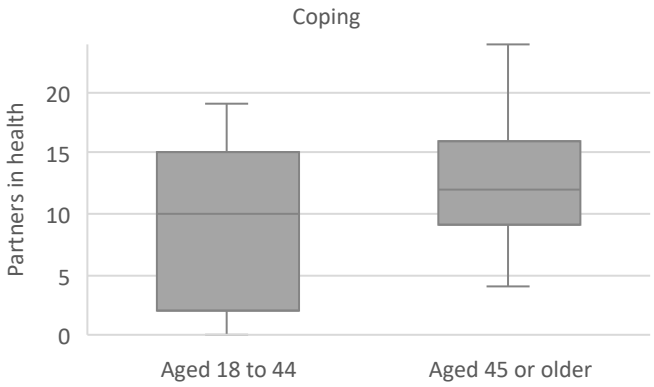

Figure 6.40: Boxplot of Partners in health: coping by age

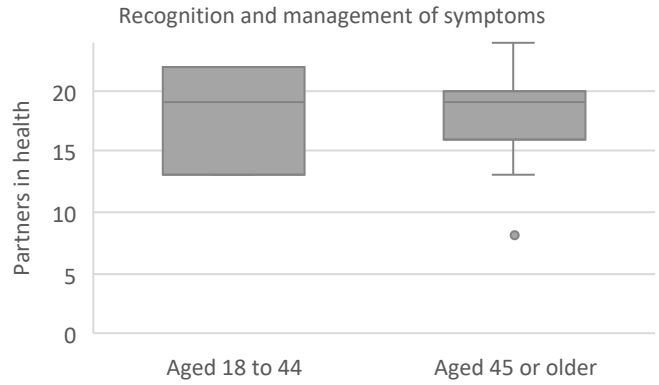

Figure 6.41: Boxplot of Partners in health: recognition and management of symptoms by age

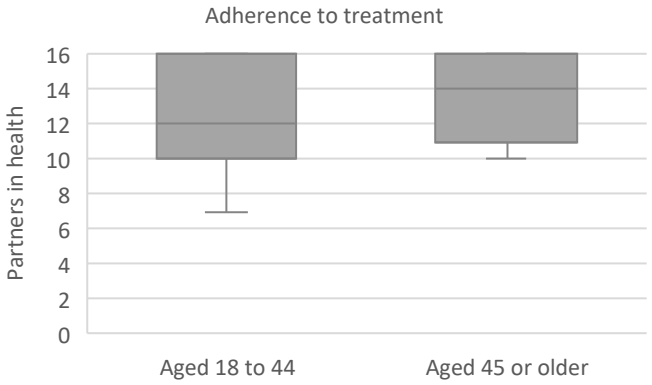

Figure 6.42: Boxplot of Partners in health: adherence to treatment by age

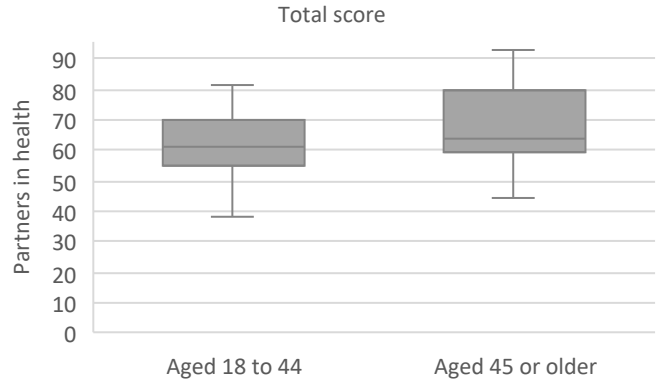

Figure 6.43: Boxplot of Partners in health Total score by age

Comparisons of Partners in health scales by gender

There were 16 females (n=16, 88.89%) with NMOSD, however, there were too few males (n=2, 11.11%) for comparisons to be made. Data by **gender** is displayed for NMOSD participants in Table 6.30, but no analysis conducted.

Table 6.30: Partners in health by gender summary statistics

Partners in health scale	Group	Number (n=18)	Percent	Mean	SD	Median	IQR
Knowledge	*Female*	16	88.89	22.75	5.08	22.00	4.25
	Male	2	11.11	25.00	9.90	25.00	7.00
Coping	*Female*	16	88.89	12.19	5.91	12.00	5.25
	Male	2	11.11	6.00	2.83	6.00	2.00
Recognition and management of symptoms	*Female*	16	88.89	18.19	3.45	19.00	4.25
	Male	2	11.11	14.00	8.49	14.00	6.00
Adherence to treatment	*Female*	16	88.89	12.63	2.70	12.00	4.50
	Male	2	11.11	15.00	1.41	15.00	1.00
Total score	*Female*	16	88.89	65.75	13.41	62.50	14.25
	Male	2	11.11	60.00	22.63	60.00	16.00

Comparisons of Partners in health scales by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. There were 15 participants with NMOSD (83.33%) that lived in Metropolitan areas, however, too few participants with NMOSD lived in Regional or remote areas (16.67%) for comparisons to be made. Data by location is displayed for NMOSD participants in Table 6.31, but no analysis conducted.

Table 6.31: Partners in health by location summary statistics

Partners in health scale	Group	Number (n=18)	Percent	Mean	SD	Median	IQR
Knowledge	*Regional and remote*	3	16.67	19.67	4.73	18.00	4.50
	Metropolitan	15	83.33	23.67	5.41	22.00	6.00
Coping	*Regional and remote*	3	16.67	8.33	4.04	9.00	4.00
	Metropolitan	15	83.33	12.13	6.16	12.00	5.50
Recognition and management of symptoms	*Regional and remote*	3	16.67	13.33	4.62	16.00	4.00
	Metropolitan	15	83.33	18.60	3.48	20.00	4.00
Adherence to treatment	*Regional and remote*	3	16.67	13.33	1.15	14.00	1.00
	Metropolitan	15	83.33	12.80	2.91	12.00	5.50
Total score	*Regional and remote*	3	16.67	54.67	10.07	56.00	10.00
	Metropolitan	15	83.33	67.20	13.82	68.00	18.50

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals (Table 6.32, Figure 6.44).

NMOSD

Participants with NMOSD were most commonly given information about treatment options (n=10, 55.56%), and disease management (n=6, 33.33%). There were five participants (27.78%) that received very little information from healthcare professionals.

MOG

All participants with MOG were given information about treatment options (n=8, 100.00%), and half of the participants were given information about disease management (n=4, 50.00%).

NMOSD or MOG

Overall, participants with NMOSD or MOG were most commonly given information about treatment options (n=18, 69.23%), disease management (n=10, 38.46%), and disease cause (n=5, 19.23%). There were five participants (19.23%) that received very little information from healthcare professionals.

Family and carers

Carers and family were most commonly given information about treatment options (n=9, 90.00%), disease management (n=6, 60.00%), and disease cause (n=4, 40.00%).

Table 6.32: Information given by health professionals

Information given by health professionals	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG		Family and carers	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent	Number (n=10)	Percent
Disease Cause	3	16.67	2	25.00	5	19.23	4	40.00
Treatment options	10	55.56	8	100.00	18	69.23	9	90.00
Disease management	6	33.33	4	50.00	10	38.46	6	60.00
Complementary therapies	0	0.00	0	0.00	0	0.00	1	10.00
Clinical trials	0	0.00	0	0.00	0	0.00	1	10.00
How to interpret test results	1	5.56	1	12.50	2	7.69	2	20.00
Dietary information	0	0.00	0	0.00	0	0.00	1	10.00
Physical activity	1	5.56	3	37.50	4	15.38	2	20.00
Psychological/social support	3	16.67	0	0.00	3	11.54	2	20.00
Hereditary considerations	0	0.00	0	0.00	0	0.00	0	0.00
None/Very little	5	27.78	0	0.00	5	19.23	0	0.00

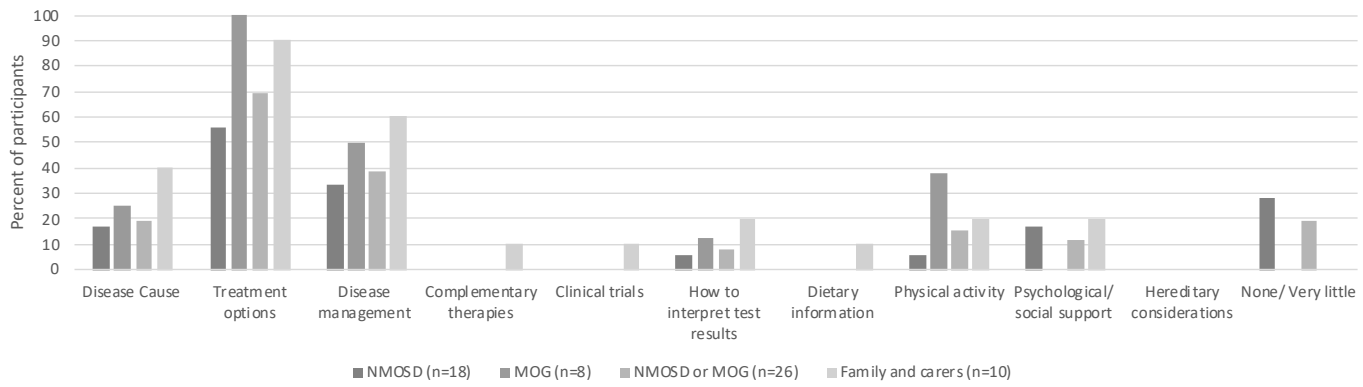

Figure 6.44: Information given by health professionals

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently (Table 6.33, Figure 6.45).

NMOSD

Participants with NMOSD most commonly searched for information about disease management (n=16, 88.89%), disease cause (n=15, 83.33%), treatment options (n=12, 66.67%), complementary therapies (n=11, 61.11%), and physical activity (n=10, 55.56%). Half of the participants looked for information about how to interpret test results, dietary information, and psychological/social support (n=9, 50.00%).

MOG

Participants with MOG most commonly searched for information about about complementary therapies (n=6, 75.00%), disease management (n=5, 62.50%), and disease Cause (n=5, 62.50%). Half of the participants looked for information about treatment options, and dietary information (n=4, 50.00%)

NMOSD or MOG

Overall, Participants with NMOSD or MOG most commonly searched for information about disease management (n=21, 80.77%), disease cause (n=20, 76.92%), complementary therapies (n=17, 65.38), and treatment options (61.54%). Half of the participants looked for information about dietary information, and physical activity (n=13, 50.00%).

Family and carers

Carers and family most commonly searched for information about disease cause (n=8, 80.00%), complementary therapies (n=8, 80.00%), disease management (n=7, 70.00%), and treatment options (n=6, 60.00%). Half of the family and carers searched for information about physical activity, how to interpret test results, and psychological/social support (n=5, 50.00%).

Table 6.33: Information searched for independently

Information searched for independently	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG		Family and carers	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent	Number (n=10)	Percent
Disease Cause	15	83.33	5	62.50	20	76.92	8	80.00
Treatment options	12	66.67	4	50.00	16	61.54	6	60.00
Disease management	16	88.89	5	62.50	21	80.77	7	70.00
Complementary therapies	11	61.11	6	75.00	17	65.38	8	80.00
Clinical trials	6	33.33	2	25.00	8	30.77	4	40.00
How to interpret test results	9	50.00	3	37.50	12	46.15	5	50.00
Dietary information	9	50.00	4	50.00	13	50.00	4	40.00
Physical activity	10	55.56	3	37.50	13	50.00	5	50.00
Psychological/social support	9	50.00	1	12.50	10	38.46	5	50.00
Hereditary considerations	8	44.44	2	25.00	10	38.46	3	30.00

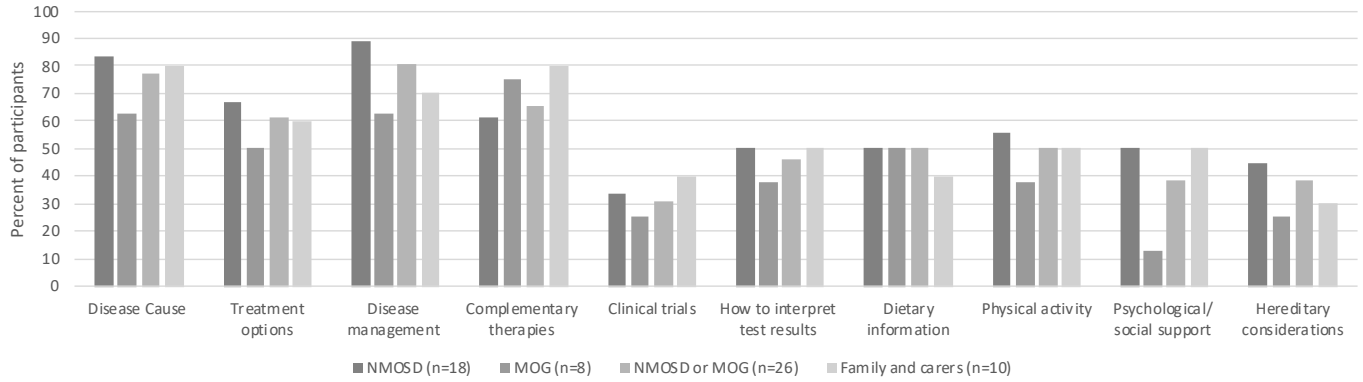

Figure 6.45: Information searched for independently

Information gaps: participants with NMOSD

The topic most often given to participants by healthcare professionals and not searched for independently was about treatment options (n = 5, 27.78%).

The topics most commonly given to participants by healthcare professionals and searched for independently were disease management (n=5, 27.78%), and treatment options (n=5, 27.78%).

Topics most often not given by health professional and not searched for independently were clinical trials (n=12, 66.67%), hereditary considerations (n=10, 55.56%), and dietary information (n=9, 50.00%).

The most common topics that were searched for and not given by a healthcare professional were disease cause (n=13, 72.22%), disease management (n=11, 61.11%), complementary therapies (n=11, 61.11%), and physical activity (n=10, 55.56%). Half of the participants searched for how to interpret test results, and dietary information without receiving information from healthcare professionals (n=9, 50.00%) (Table 6.34, Figure 6.46).

Table 6.34: Information gaps: participants with NMOSD

NMOSD	Given by health professional only		Given by health professional, searched for independently		Not given by health professional, not searched for independently		Searched for independently only	
	n=18	Percent	n=18	Percent	n=18	Percent	n=18	Percent
Disease Cause	1	5.56	2	11.11	2	11.11	13	72.22
Treatment options	5	27.78	5	27.78	1	5.56	7	38.89
Disease management	1	5.56	5	27.78	1	5.56	11	61.11
Complementary therapies	0	0.00	0	0.00	7	38.89	11	61.11
Clinical trials	0	0.00	0	0.00	12	66.67	6	33.33
How to interpret test results	1	5.56	0	0.00	8	44.44	9	50.00
Dietary information	0	0.00	0	0.00	9	50.00	9	50.00
Physical activity	1	5.56	0	0.00	7	38.89	10	55.56
Psychological/social support	2	11.11	1	5.56	7	38.89	8	44.44
Hereditary considerations	0	0.00	0	0.00	10	55.56	8	44.44

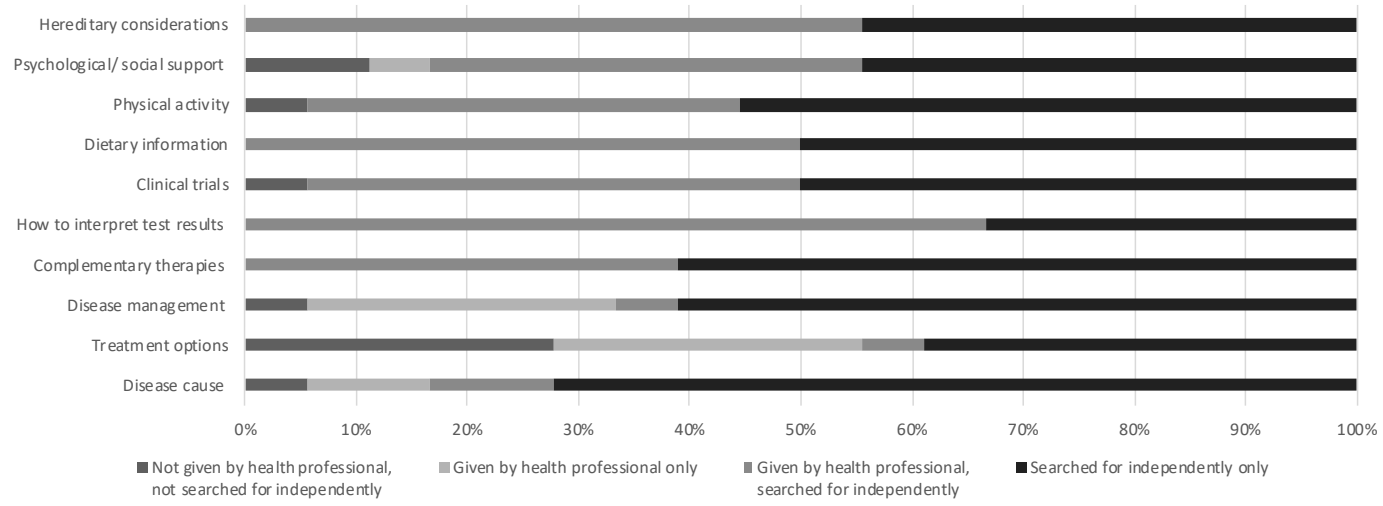

Figure 6.46: Information gaps: participants with NMOSD

Most accessed information

Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 5 is the least trusted. A weighted average is presented in Table 6.35 and Figure 6.47. With a weighted ranking, the higher the score, the more accessed the source of information.

NMOSD

Participants with NMOSD accessed information from non-profits organisations, charities, or patient organisations most often, followed by medical journals, and from the government least often

MOG

Participants with MOG accessed information from medical journals, most often, followed by non-profits organisations, charities, or patient organisations and from the government least often

NMOSD or MOG

Participants with NMOSD or MOG accessed information from medical journals, most often, followed by non-profits organisations, charities, or patient organisations and from the government least often

Family and carers

Family and carers accessed information from non-profits organisations, charities, or patient organisations most often, followed by medical journals, and from the government least often.

Table 6.35: Most accessed information

Information source	NMOSD	MOG	NMOSD or MOG	Family or carers
Non-profit organisations, charity or patient organisations	3.83	3.00	3.58	4.00
Government	2.33	2.63	2.42	1.80
Pharmaceutical companies	2.44	2.88	2.58	2.50
Hospital or clinic I am being treated in	2.67	2.75	2.69	3.30
Medical journals	3.72	3.75	3.73	3.40

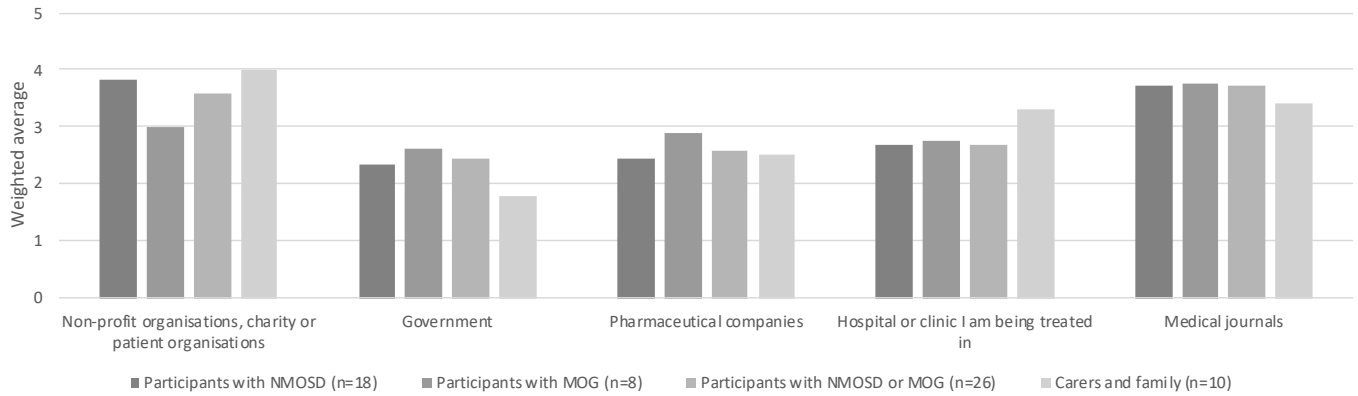

Figure 6.47: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. Participants were asked if they had accessed it (Table 6.36, Figure 6.48), and if they had accessed it, how useful it was (Table 6.37, Figure 6.49).

NMOSD

There were nine participants with NMOSD (50.00%) that had accessed My Health Record, seven participants (38.89%) that had not. There was one participant (5.56%) that wasn't sure, and one participant (5.56%) that's did not know what it is.

Of those that had accessed My Health Record, there were three participants (33.33%) that thought the usefulness was very poor, two participants (22.22%) that thought it was poor, and four participants (44.44%) found it acceptable)

MOG

There were two participants with MOG (25.00%) that had accessed My Health Record, five participants (62.50%) that had not. There was one participant (12.50%) that's did not know what it is.

NMOSD or MOG

There were 11 participants with NMOSD or MOG (42.31%) that had accessed My Health Record, 12 participants (46.15%) that had not. There was one participant (3.85%) that wasn't sure, and two participants (7.69%) that's did not know what it is.

Of those that had accessed My Health Record, there were four participants (36.36%) that thought the usefulness was very poor, two participants (18.18%) that thought it was poor, and five participants (45.45%) found it acceptable)

Family and carers

There were three family and carers (30.00%) that had accessed My Health Record, seven participants (70.00%) that had not.

Table 6.36: Accessed My Health Record

Accessed My Health Record	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG		Family and carers	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent	Number (n=10)	Percent
Yes	9	50.00	2	25.00	11	42.31	3	30.00
No	7	38.89	5	62.50	12	46.15	7	70.00
I am not sure	1	5.56	0	0.00	1	3.85	0	0.00
I don't know what 'My Health Record' is	1	5.56	1	12.50	2	7.69	0	0.00

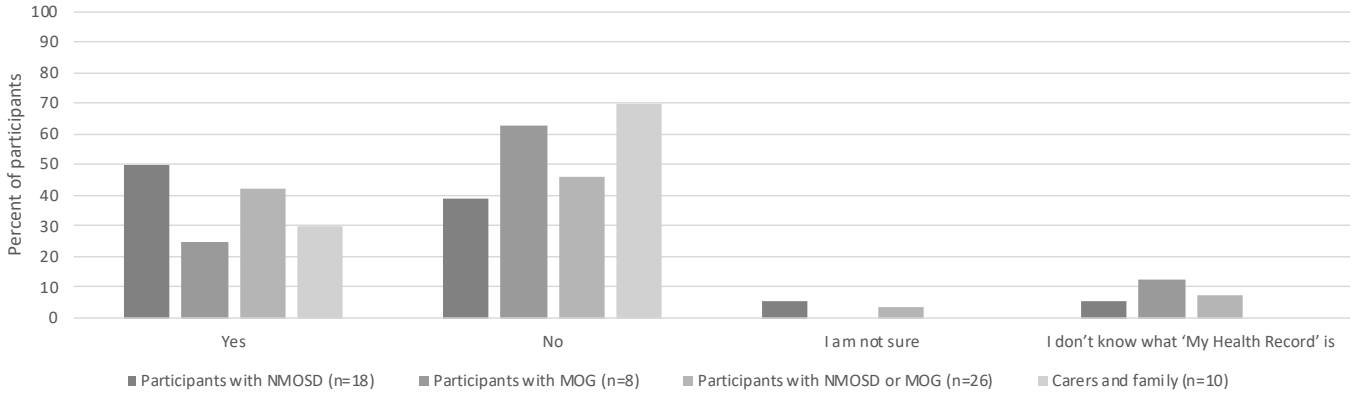

Figure 6.48: Accessed My Health Record

Table 6.37: How useful was My Health Record

How useful was My Health Record	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG		Family and carers	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent	Number (n=10)	Percent
Very poor	3	33.33	1	50.00	4	36.36	2	66.67
Poor	2	22.22	0	0.00	2	18.18	0	0.00
Acceptable	4	44.44	1	50.00	5	45.45	1	33.33
Good	0	0.00	0	0.00	0	0.00	0	0.00
Very good	0	0.00	0	0.00	0	0.00	0	0.00

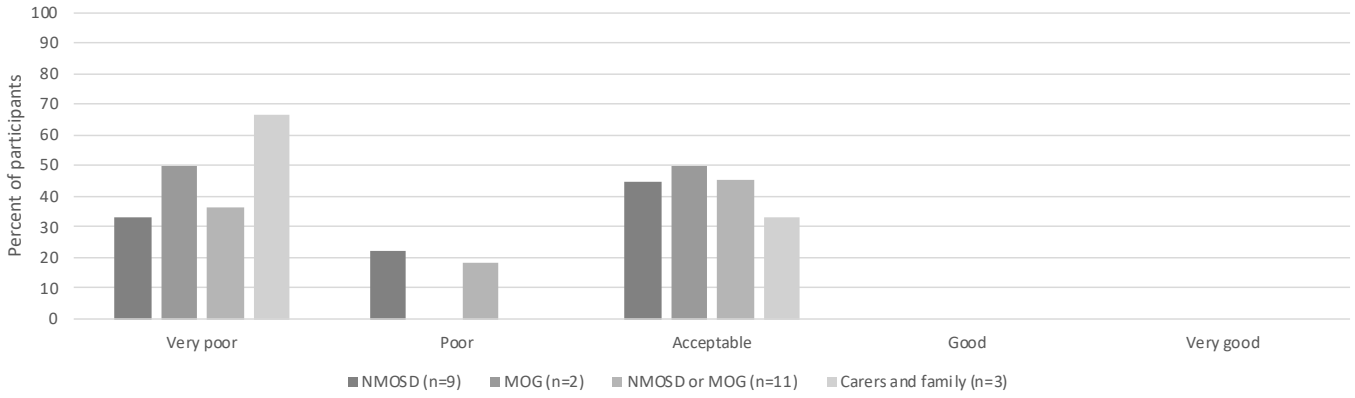

Figure 6.49: How useful was My Health Record

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome.

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had poor communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had a moderate navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had moderate communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as moderate.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as good.

Ability to take medicine as prescribed

Participants were asked about their ability to take medicines as prescribed. The majority of participants with NMOSD responded that they took medicine as prescribed all the time (n=11, 61.11%), and seven participants (38.89%) responded that they took medicines as prescribed most of the time. There were no participants that responded that they sometime, never, or rarely took medicines as prescribed.

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. In the general NMOSD population the most common response was that participants and no received any support (n=8, 44.44%). This was followed by receiving support through domestic services (n=7, 38.89%).

Care coordination

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 7.1.

Overall, the participants in this PEEK study had an average score in the second highest quintile for **Care coordination: Quality of care global measure** (median=7.00, IQR=3.00) indicating good quality of care.

The average scores for **Care coordination: navigation** (mean = 22.19, SD = 4.68), **Care coordination: Total score** (mean = 55.33, SD = 9.97), and **Care coordination: Care coordination global measure** (mean=5.97, SD=2.13) were in the middle of the scale indicating moderate healthcare navigation and overall experience of care coordination.

The average score for **Care coordination: communication** (median=32.50, IQR=8.00) was in the second lowest quintile, indicating poor healthcare communication.

Comparisons of Care co-ordination have been made based on **participant type** (Tables 7.2 to 7.3, Figures 7.1 to 7.5), **relapse** (Tables 7.4 to 7.5, Figures 7.6 to 7.10), **fear of progression** (Tables 7.6 to 7.7, Figures 7.16 to 7.20), **physical function** (Tables 7.8 to 7.9, Figures 7.16 to 7.20), **education** (Tables 7.10 to 7.11, Figures 7.21 to 7.25), **socioeconomic status** (Tables 7.12 to 7.13, Figures 7.26 to 7.30), **age** (Tables 7.14 to 7.15, Figures 7.31 to 7.35), **gender** (Tables 7.16) and **location** (Table 7.17).

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had poor communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had a moderate navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had moderate communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as moderate.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as good.

Table 7.1: Care coordination summary statistics

Care coordination scale (n=36)	Mean	SD	Median	IQR	Possible range	Quintile
Communication	33.14	7.31	32.50	8.00	13 to 65	2.00
Navigation*	22.19	4.68	23.00	6.00	7 to 35	3.00
Total score*	55.33	9.97	56.00	11.25	20 to 100	3.00
Care coordination global measure*	5.97	2.13	6.00	2.25	1 to 10	3.00
Quality of care global measure	6.47	2.16	7.00	3.00	1 to 10	4.00

*Normal distribution use mean and SD as average measure

Comparisons of Care coordination scales by participant type

Participant type were grouped according to diagnosis of NMOSD, MOG, and family and carers; the *NMOSD* group includes participants who had a NMOSD diagnosis, (n=18, 50.00%), participants who had a MOG diagnosis were included in the *MOG* group (n=8, 22.22%), participants in the *NMOSD or MOG* groups were included in the *NMOSD or MOG* subgroup (n=26, 72.22), and family members or carers of people with NMOSD or MOG were included in the *Family and carers* subgroup (n=10, 27.78%).

Boxplots of each Care coordination scale by **participant type** are displayed in Figures 7.1 to 7.5, summary statistics are displayed in Tables 7.2 and 7.3.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 7.2).

When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 7.3).

No significant differences were observed between participants by **participant type** for any of the Care coordination scales.

Table7.2: Care coordination by participant type ANOVA test

Care coordination scale	Group	Number (n=36)	Percent	Median	IQR	C^2	dF	p-value
Communication	NMOSD	18	50.00	29.50	6.00	6.45	3	0.0917
	MOG	8	22.22	36.50	3.00			
	NMOSD and MOG	26	72.22	31.00	8.75			
	Family and carers	10	27.78	33.00	4.25			

Table7.3: Care coordination by participant type Kruskal-Wallis test

Care coordination scale	Group	Number (n=36)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Navigation	NMOSD	18	50.00	20.56	4.84	Between groups	103.30	3	34.43	1.56	0.2080
	MOG	8	22.22	23.75	4.68	Within groups	1277.30	58	22.02		
	NMOSD and MOG	26	72.22	21.54	4.93	Total	1380.60	61			
	Family and carers	10	27.78	23.90	3.60						
Total score	NMOSD	18	50.00	51.50	11.16	Between groups	590.00	3	196.60	1.88	0.1430
	MOG	8	22.22	61.00	8.86	Within groups	6069.00	58	104.60		
	NMOSD and MOG	26	72.22	54.42	11.25	Total	6659.00	61			
	Family and carers	10	27.78	57.70	5.12						
Care coordination global measure	NMOSD	18	50.00	5.67	2.20	Between groups	11.04	3	3.68	0.85	0.4740
	MOG	8	22.22	7.00	1.31	Within groups	251.95	58	4.34		
	NMOSD and MOG	26	72.22	6.08	2.04	Total	262.99	61			
	Family and carers	10	27.78	5.70	2.45						
Quality of care global measure	NMOSD	18	50.00	6.00	2.50	Between groups	9.49	3	3.16	0.67	0.5770
	MOG	8	22.22	7.25	1.04	Within groups	275.75	58	4.75		
	NMOSD and MOG	26	72.22	6.38	2.21	Total	285.24	61			
	Family and carers	10	27.78	6.70	2.11						

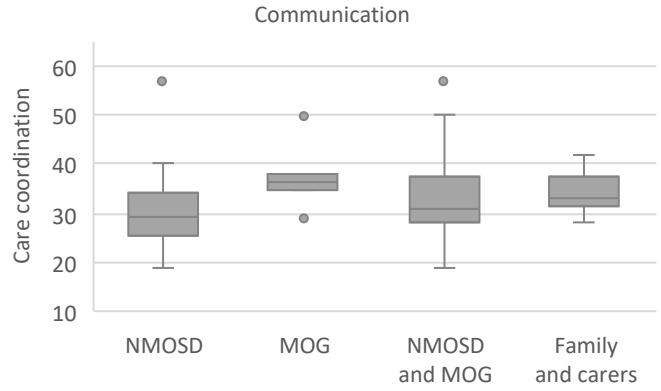

Figure 7.1: Boxplot of Care coordination: Communication by participant type

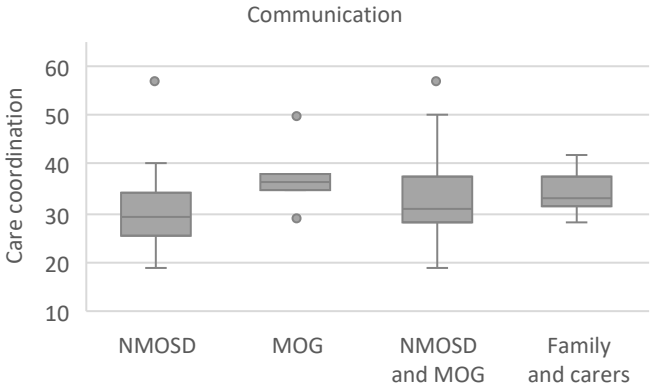

Figure 7.2: Boxplot of Care coordination: Navigation by participant type

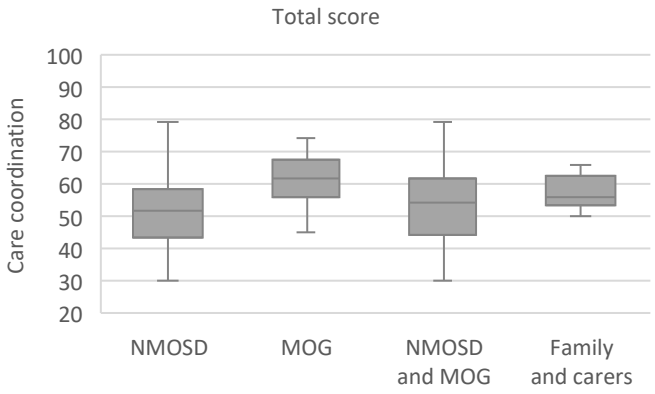

Figure 7.3: Boxplot of Care coordination: Total score by participant type

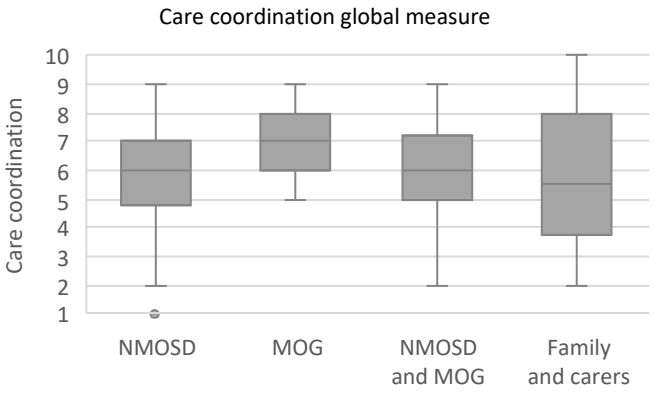

Figure 7.4: Boxplot of Care coordination: Care coordination global measure by participant type

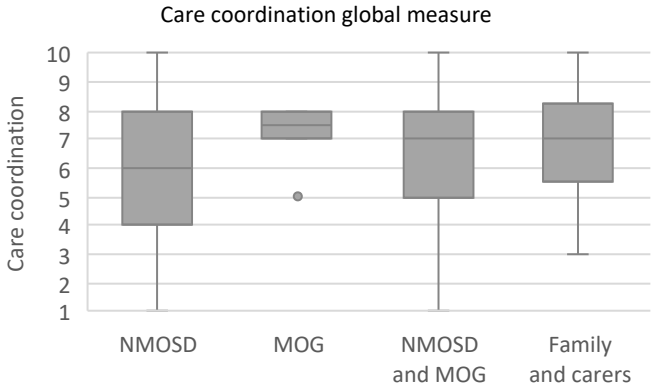

Figure 7.5: Boxplot of Care coordination: Quality of care global measure by participant type

Comparisons of Care coordination scales by relapse

Comparisons were made by NMOSD relapses, those less than two relapses were included in the *fewer relapses* subgroup (n=9, 50.00%), and those that had three or more relapses, in the *more relapses* subgroup (n=9, 50.00%). Only participants with NMOSD were included in this comparison.

Boxplots of each Care coordination scale by **relapse** are displayed in Figures 7.6 to 7.10, summary statistics are displayed in Tables 7.4 to 7.5. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.4), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.5).

No significant differences were observed between participants in the *fewer relapses* subgroup compared to those in the *more relapses* subgroup for any of the Care coordination scales.

Table 7.4: Care coordination by relapse summary statistics and two sample t-test

Care coordination scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Navigation	*Fewer relapses*	9	50.00	22.22	4.09	1.52	16	0.1492
	More relapses	9	50.00	18.89	5.18			
Total score	*Fewer relapses*	9	50.00	52.89	12.30	0.52	16	0.6125
	More relapses	9	50.00	50.11	10.43			
Care coordination global measure	*Fewer relapses*	9	50.00	5.78	2.11	0.21	16	0.8375
	More relapses	9	50.00	5.56	2.40			
Quality of care global measure	*Fewer relapses*	9	50.00	6.44	2.13	0.75	16	0.4670
	More relapses	9	50.00	5.56	2.88			

Table 7.5: Care coordination by relapse summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Communication	*Fewer relapses*	9	50.00	29.00	5.00	33.5	0.5652
	More relapses	9	50.00	30.00	9.00		

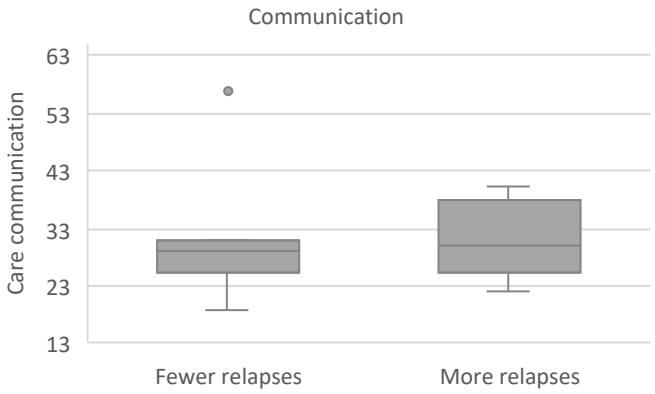

Figure 7.6: Boxplot of Care coordination: Communication by relapse

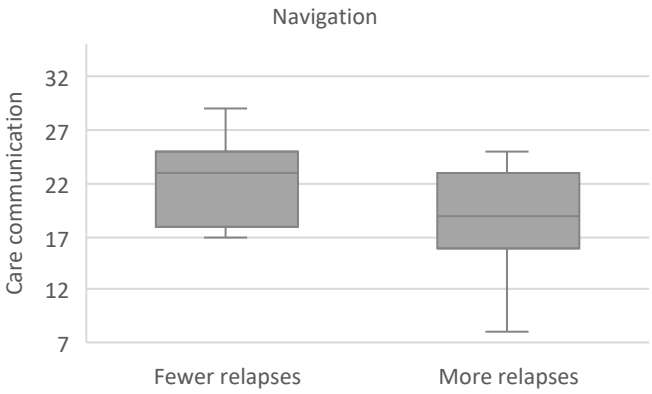

Figure 7.7: Boxplot of Care coordination: Navigation by relapse

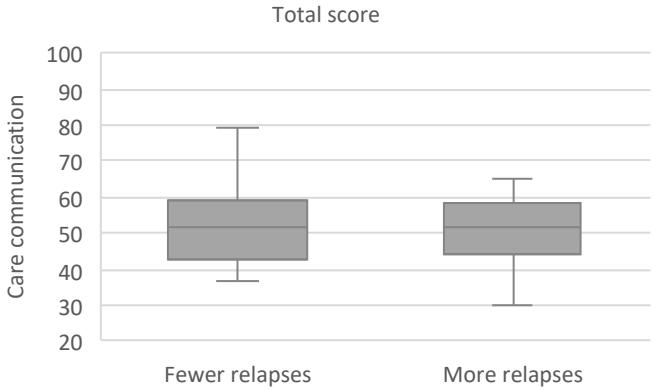

Figure 7.8: Boxplot of Care coordination: Total score by relapse

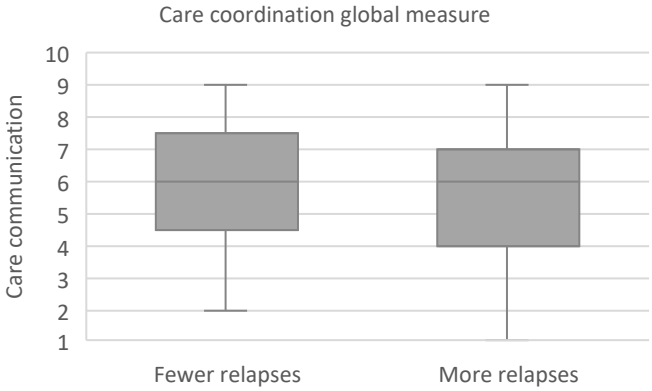

Figure 7.9: Boxplot of Care coordination: Care coordination global measure by relapse

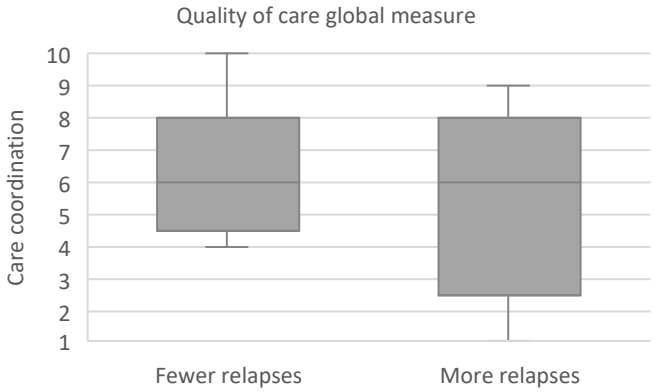

Figure 7.10: Boxplot of Care coordination: Quality of care global measure by relapse

Comparisons of Care coordination scales by fear of progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Participants that scored over 41 in the Fear of progression questionnaire were included in the High to very high fear subgroup (n=10, 55.56%), and those that scored less than 41 were included in the Low to moderate fear subgroup (n=8, 44.44%). Only participants with NMOSD were included in this comparison.

Boxplots of each Care coordination scale by **fear of progression** are displayed in Figures 7.11 to 7.15, summary statistics are displayed in Tables 7.6 to 7.7. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.6), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.7).

No significant differences were observed between participants in the *Low to moderate fear* subgroup compared to those in the *High to very high fear* subgroup for any of the Care coordination scales.

Table 7.6: Care coordination by fear of progression summary statistics and two sample t-test

Care coordination scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Navigation	*Low to moderate fear*	8	44.44	21.75	4.37	0.93	16	0.3649
	High to very high fear	10	55.56	19.60	5.21			
Total score	*Low to moderate fear*	8	44.44	53.00	7.09	0.50	16	0.6248
	High to very high fear	10	55.56	50.30	13.87			
Care coordination global measure	*Low to moderate fear*	8	44.44	6.25	2.49	1.01	16	0.3283
	High to very high fear	10	55.56	5.20	1.93			
Quality of care global measure	*Low to moderate fear*	8	44.44	6.88	1.96	1.36	16	0.1918
	High to very high fear	10	55.56	5.30	2.75			

Table 7.7: Care coordination by fear of progression summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Communication	*Low to moderate fear*	8	44.44	31.00	6.50	49.50	0.4229
	High to very high fear	10	55.56	29.00	5.75		

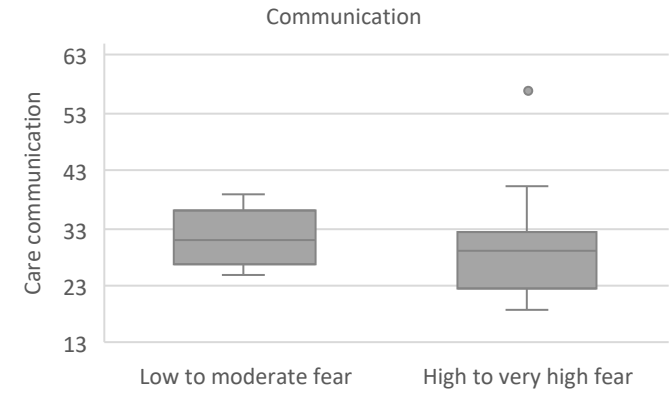

Figure 7.11: Boxplot of Care coordination: Communication by fear of progression

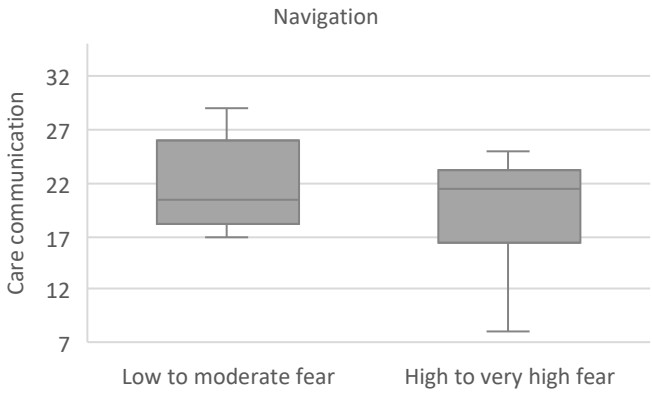

Figure 7.12: Boxplot of Care coordination: Navigation by fear of progression

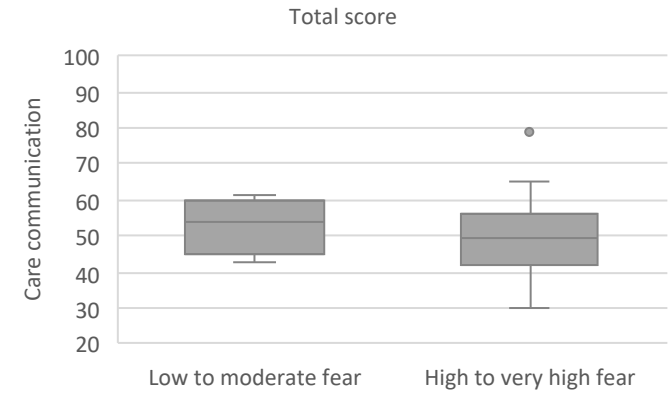

Figure 7.13: Boxplot of Care coordination: Total score by fear of progression

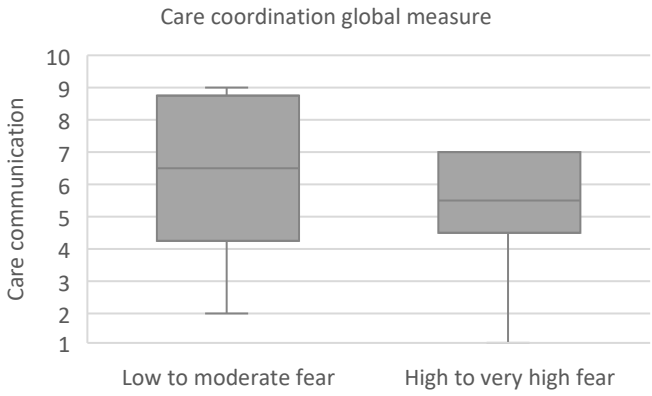

Figure 7.14: Boxplot of Care coordination: Care coordination global measure by fear of progression

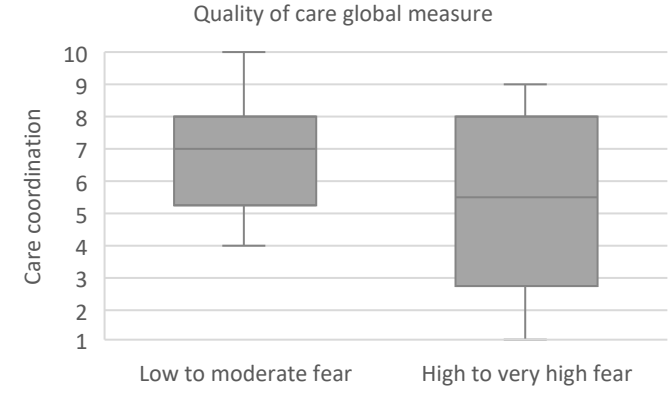

Figure 7.15: Boxplot of Care coordination: Quality of care global measure by fear of progression

Comparisons of Care coordination scales by physical function

The SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. Comparisons were made by **physical function**, participants that scored in the lowest three quintiles of the SF36 Physical functioning scale were included in the *Moderate to very poor physical function* subgroup (n=9, 50.00%), and participants that scored in the highest two quintiles were included in the *Good to very good physical function* subgroup (n=9, 50.00%). Only participants with NMOSD were included in this comparison.

Boxplots of each Care coordination scale by **physical function** are displayed in Figures 7.16 to 7.20, summary statistics are displayed in Tables 7.8 to 7.9.

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.8), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.9).

No significant differences were observed between participants in the *Moderate to very poor physical function* subgroup compared to those in the *Good to very good physical function* subgroup for any of the care coordination scales.

Table 7.8: Care coordination by physical function summary statistics and two sample t-test

Care coordination scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Navigation	*Moderate to very poor physical function*	9	50.00	20.89	5.82	0.28	16	0.7800
	Good to very good physical function	9	50.00	20.22	3.96			
Care coordination global measure	*Moderate to very poor physical function*	9	50.00	5.78	2.49	0.21	16	0.8375
	Good to very good physical function	9	50.00	5.56	2.01			
Quality of care global measure	*Moderate to very poor physical function*	9	50.00	6.56	2.30	0.94	16	0.3608
	Good to very good physical function	9	50.00	5.44	2.70			

Table 7.9: Care coordination by physical function summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Communication	*Moderate to very poor physical function*	9	50.00	30.00	10.00	39.5	0.9647
	Good to very good physical function	9	50.00	29.00	3.00		
Total score	*Moderate to very poor physical function*	9	50.00	52.00	16.00	43.5	0.8247
	Good to very good physical function	9	50.00	52.00	12.00		

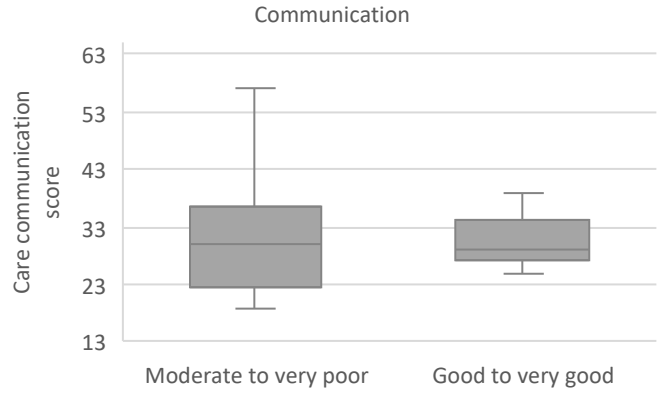

Figure 7.16: Boxplot of Care coordination: Communication by physical function

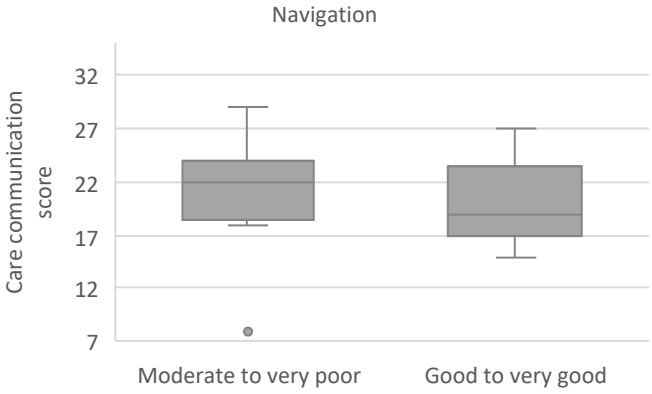

Figure 7.17: Boxplot of Care coordination: Navigation by physical function

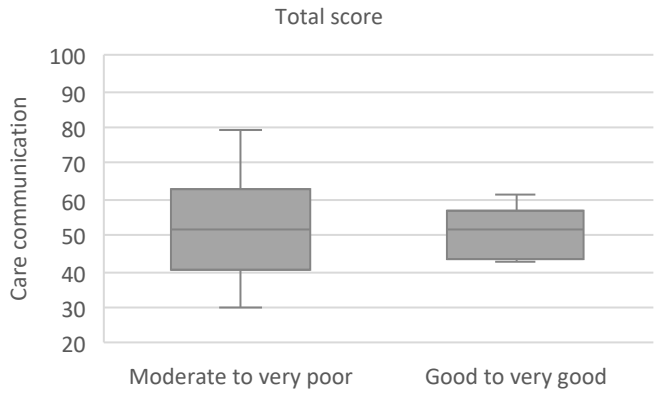

Figure 7.18: Boxplot of Care coordination: Total score by physical function

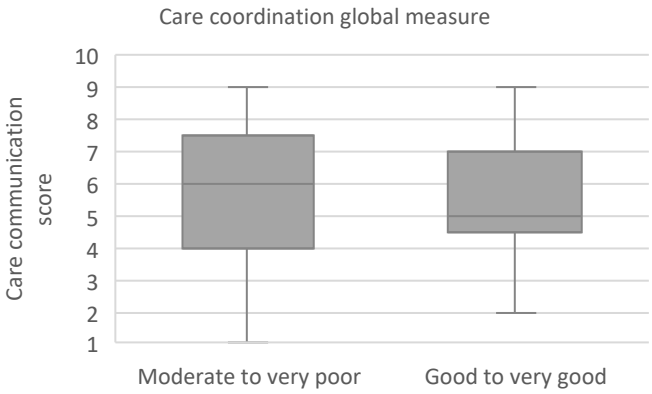

Figure 7.19: Boxplot of Care coordination: Care coordination global measure by physical function

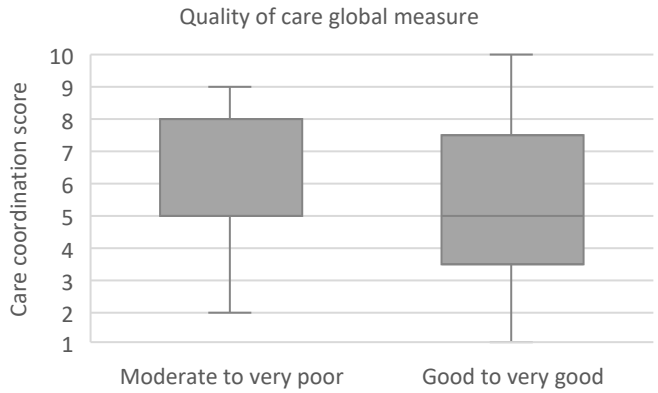

Figure 7.20: Boxplot of Care coordination: Quality of care global measure by physical function

Comparisons of Care coordination scales by education

Comparisons were made by Education status, between those with trade or high school qualifications, *trade or high school* (n=10, 55.56%), and those with a university qualification, *University* (n= 8, 44.44%). Only participants with NMOSD were included in this comparison.

Boxplots of each Care coordination scale by **education** are displayed in Figures 7.21 to 7.25, summary statistics are displayed in Tables 7.10 to 7.11. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.10), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.11).

No significant differences were observed between participants in the *trade or high school* subgroup compared to those in the *University* subgroup for any of the Care coordination scales.

Table 7.10: Care coordination by education summary statistics and two sample t-test

Care coordination scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Navigation	*Trade or high school*	10	55.56	18.70	4.90	-1.97	16	0.0670
	University	8	44.44	22.88	3.87			
Care coordination global measure	*Trade or high school*	10	55.56	5.30	2.26	-0.78	16	0.4451
	University	8	44.44	6.13	2.17			
Quality of care global measure	*Trade or high school*	10	55.56	5.70	2.83	-0.56	16	0.5844
	University	8	44.44	6.38	2.13			

Table 7.11: Care coordination by education summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Communication	*Trade or high school*	10	55.56	28.50	8.75	29.50	0.3733
	University	8	44.44	30.50	3.75		
Total score	*Trade or high school*	10	55.56	45.50	8.75	24.50	0.1812
	University	8	44.44	54.50	6.75		

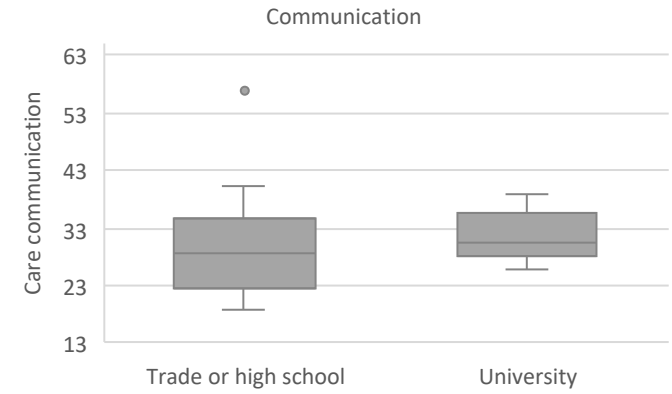

Figure 7.21: Boxplot of Care coordination: Communication by education

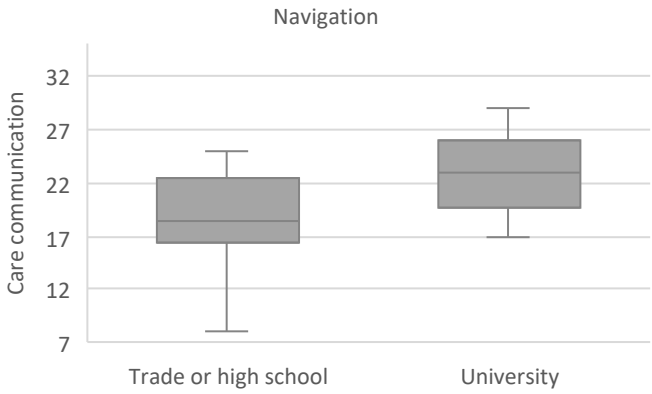

Figure 7.22: Boxplot of Care coordination: Navigation by education

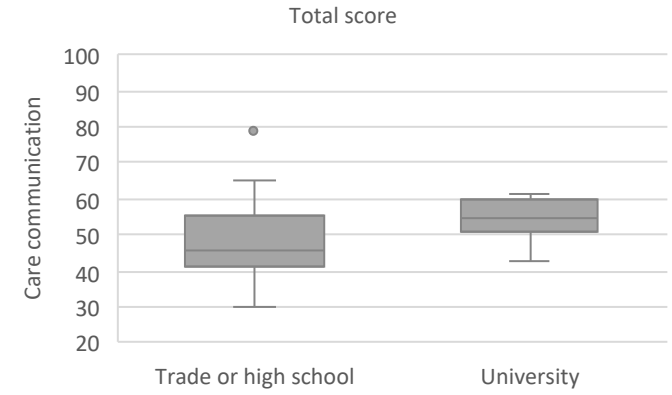

Figure 7.23: Boxplot of Care coordination: Total score by education

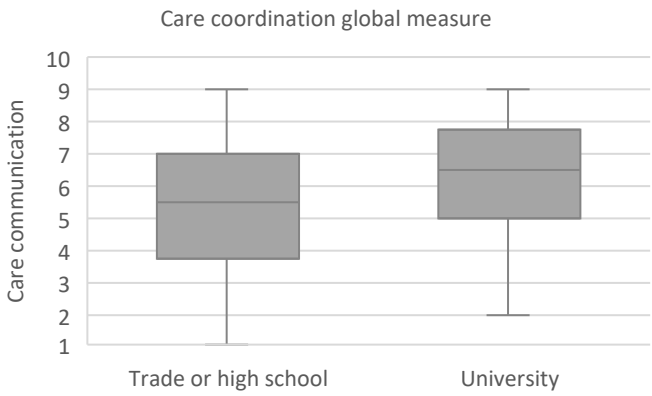

Figure 7.24: Boxplot of Care coordination: Care coordination global measure by education

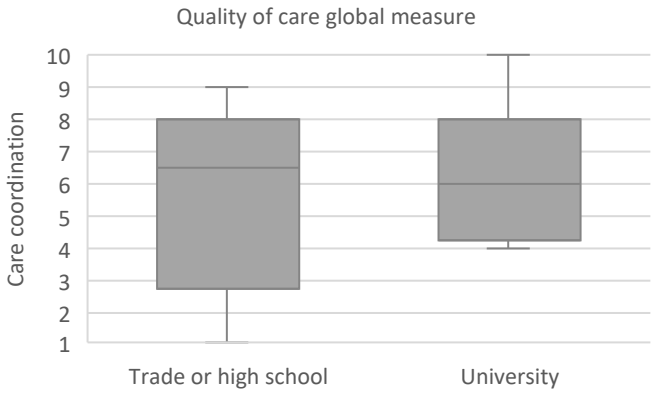

Figure 7.25: Boxplot of Care coordination: Quality of care global measure by education

Comparisons of Care coordination scales by socioeconomic status

Comparisons were made by **socioeconomic status**, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, *mid to low status* (n=6, 33.33%) compared to those with a higher SEIFA score of 7-10, *higher status* (n=12, 66.67%). Only participants with NMOSD were included in this comparison.

Boxplots of each Care coordination scale by **socioeconomic status** are displayed in Figures 7.26 to 7.30, summary statistics are displayed in Tables 7.12 to 7.13. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.12), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.13).

A two sample t-test indicated that the mean score for the **Care coordination: navigation** scale[t(16) = -2.37 p=0.0309] was significantly higher for participants in the *Higher status* subgroup (Mean = 22.25, SD = 3.96) compared to participants in the *Mid to low status* subgroup (Mean = 17.17, SD = 4.96).

A two sample t-test indicated that the mean score for the **Care coordination: total score** scale [t(16) = -2.45, p=0.0264] was significantly higher for participants in the *Higher status* subgroup (Mean = 55.50, SD = 10.26) compared to participants in the *Mid to low status* subgroup (Mean = 43.50, SD = 8.73).

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. On average, participants in the *Higher status* subgroup scored higher than participants in the *Mid to low status* subgroup. This indicates that participants in the *Higher status* subgroup, had moderate navigation of the healthcare system, compared to poor navigation for participants in the *Mid to low status* subgroup.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in the *Higher status* subgroup scored higher than participants in the *Mid to low status* subgroup. On average, participants in the *Higher status* subgroup scored higher than participants in the *Mid to low status* subgroup. This indicates that participants in the *High status* subgroup, had moderate communication, navigation and overall experience of care coordination, compared to poor communication and navigation and overall experience of care coordination for participants in the *Mid to low status* subgroup.

Table 7.12: Care coordination by socioeconomic status summary statistics and two sample t-test

Care coordination scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Navigation	*Mid to low status*	6	33.33	17.17	4.96	-2.37	16	0.0309*
	Higher status	12	66.67	22.25	3.96			
Total score	*Mid to low status*	6	33.33	43.50	8.73	-2.45	16	0.0264*
	Higher status	12	66.67	55.50	10.26			
Care coordination global measure	*Mid to low status*	6	33.33	5.00	2.61	-0.91	16	0.3785
	Higher status	12	66.67	6.00	2.00			
Quality of care global measure	*Mid to low status*	6	33.33	4.83	2.93	-1.45	16	0.1675
	Higher status	12	66.67	6.58	2.15			

*Significant at p<0.05

Table 7.13: Care coordination by socioeconomic status summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Communication	*Mid to low status*	6	33.33	27.00	7.00	19.00	0.1215
	Higher status	12	66.67	30.50	9.50		

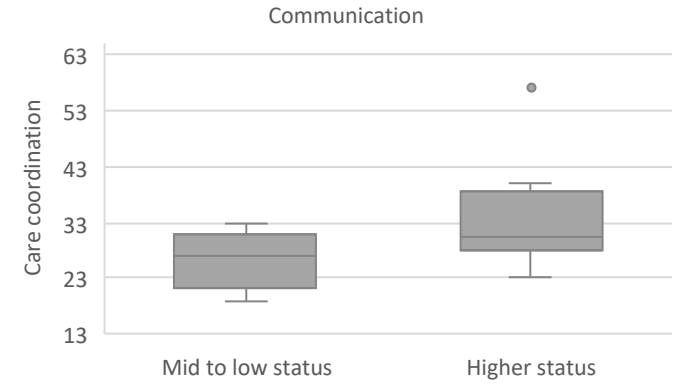

Figure 7.26: Boxplot of Care coordination: Communication by socioeconomic status

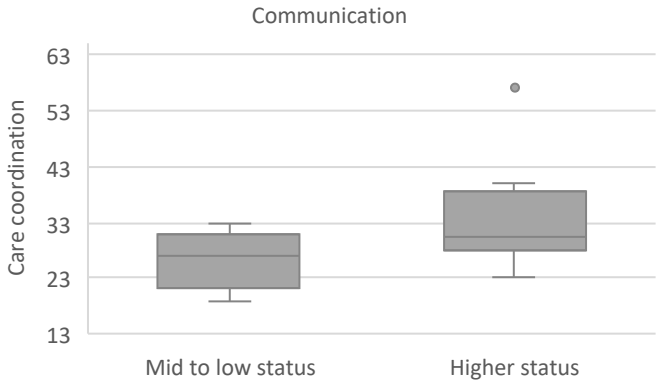

Figure 7.27: Boxplot of Care coordination: Navigation by socioeconomic status

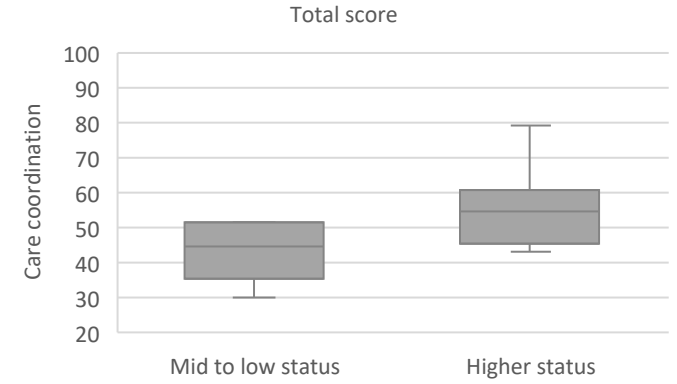

Figure 7.28: Boxplot of Care coordination: Total score by socioeconomic status

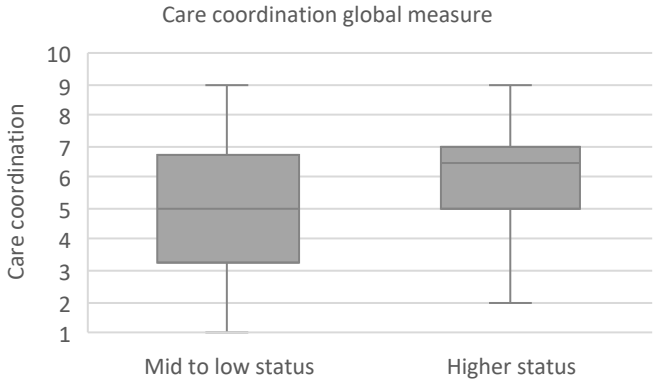

Figure 7.29: Boxplot of Care coordination: Care coordination global measure by socioeconomic status

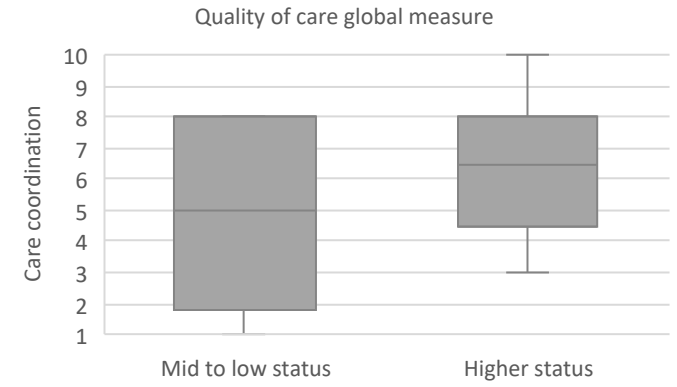

Figure 7.30: Boxplot of Care coordination: Quality of care global measure by socioeconomic status

Comparisons of Care coordination scales by age

Participants were grouped according to **age,** with comparisons made between participants *Aged 18 to 44* (n=7, 38.89%), and *Aged 45 or older* (n=11, 61.11%). Only participants with NMOSD were included in this comparison.

Boxplots of each Care coordination scale by **age** are displayed in Figures 7.31 to 7.35, summary statistics are displayed in Tables 7.14 to 7.15.

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.14), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.15).

No significant differences were observed between participants in the *Aged 18 to 44* subgroup compared to those in the *Aged 45 or older* subgroup for any of the care coordination scales.

Table 7.14: Care coordination by age summary statistics and two sample t-test

Care coordination scale	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Total score	*Aged 18 to 44*	7	38.89	49.57	11.18	-0.57	16	0.5744
	Aged 45 or older	11	61.11	52.73	11.51			
Care coordination global measure	*Aged 18 to 44*	7	38.89	5.14	2.67	-0.80	16	0.4362
	Aged 45 or older	11	61.11	6.00	1.90			
Quality of care global measure	*Aged 18 to 44*	7	38.89	5.00	2.38	-1.39	16	0.1829
	Aged 45 or older	11	61.11	6.64	2.46			

Table 7.15: Care coordination by age summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=18)	Percent	Median	IQR	W	p-value
Communication	*Aged 18 to 44*	7	38.89	30.00	6.50	41.5	0.8205
	Aged 45 or older	11	61.11	29.00	5.50		
Navigation	*Aged 18 to 44*	7	38.89	19.00	6.50	27.5	0.3396
	Aged 45 or older	11	61.11	22.00	5.00		

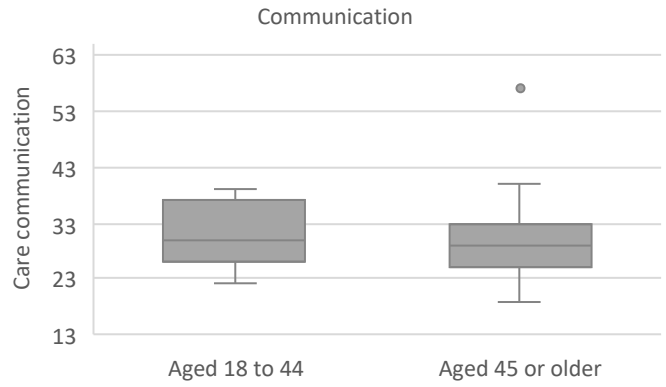

Figure 7.31: Boxplot of Care coordination: Communication by age

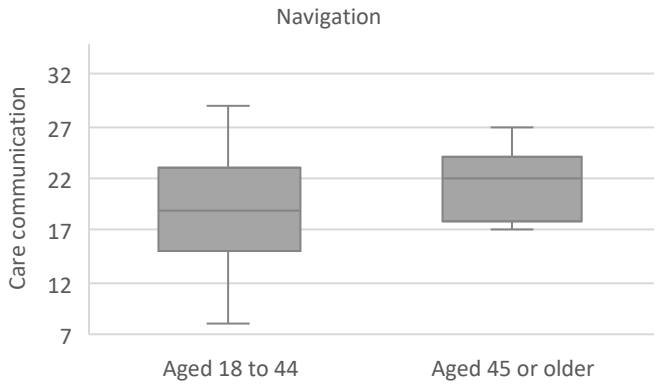

Figure 7.32: Boxplot of Care coordination: Navigation by age

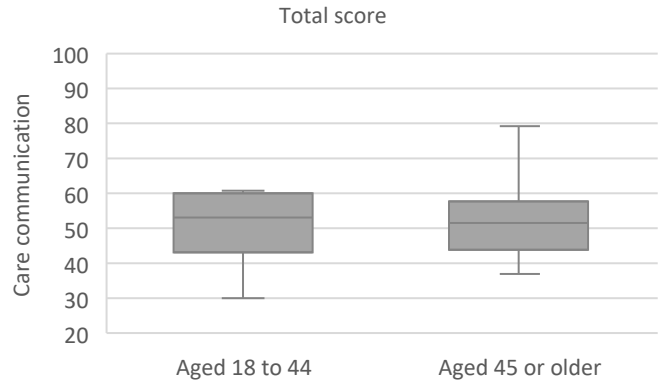

Figure 7.33: Boxplot of Care coordination: Total score by age

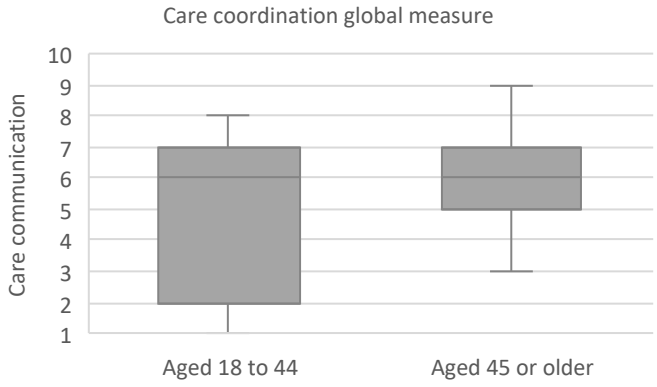

Figure 7.34: Boxplot of Care coordination: Care coordination global measure by age

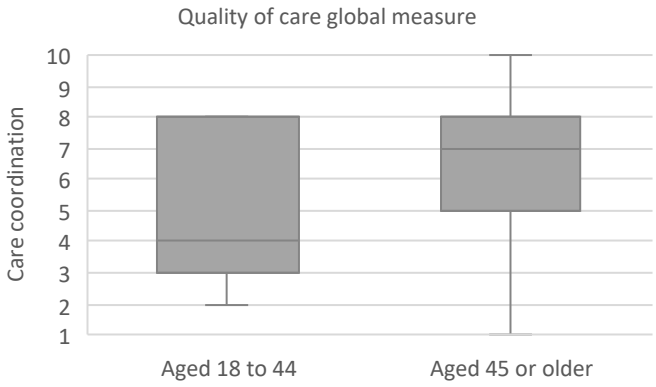

Figure 7.35: Boxplot of Care coordination: Quality of care global measure by age

Comparisons of Care coordination scales by gender

There were 16 females (n=16, 88.89%) with NMOSD, however, there were too few males (n=2, 11.11%) for comparisons to be made. Data by gender is displayed for NMOSD participants in Table 7.16, but no analysis conducted.

Table 7.16: Care coordination by gender summary statistics

Care coordination scale	Group	Number (n=18)	Percent	Mean	SD	Median	IQR
Communication	*Female*	16	88.89	31.13	8.22	29.50	4.00
	Male	2	11.11	29.50	14.85	29.50	10.50
Navigation	*Female*	16	88.89	20.44	4.98	21.50	5.25
	Male	2	11.11	21.50	4.95	21.50	3.50
Total score	*Female*	16	88.89	51.56	10.72	52.00	12.50
	Male	2	11.11	51.00	19.80	51.00	14.00
Care coordination global measure	*Female*	16	88.89	5.56	2.31	5.50	2.25
	Male	2	11.11	6.50	0.71	6.50	0.50
Quality of care global measure	*Female*	16	88.89	5.69	2.47	6.00	4.00
	Male	2	11.11	8.50	0.71	8.50	0.50

Comparisons of Care coordination scales by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. There were 15 participants with NMOSD (83.33%) that lived in Metropolitan areas, however, too few participants with NMOSD lived in Regional or remote areas (16.67%) for comparisons to be made. Data by location is displayed for NMOSD participants in Table 6.17, but no analysis conducted.

Table 7.17: Care coordination by location summary statistics

Care coordination scale	Group	Number (n=18)	Percent	Mean	SD	Median	IQR
Communication	*Regional or remote*	3	16.67	27.33	7.37	30.00	7.00
	Metropolitan	15	83.33	31.67	8.80	29.00	7.00
Navigation	*Regional or remote*	3	16.67	18.00	1.00	18.00	1.00
	Metropolitan	15	83.33	21.07	5.16	22.00	5.00
Total score	*Regional or remote*	3	16.67	45.33	7.64	47.00	7.50
	Metropolitan	15	83.33	52.73	11.54	52.00	15.00
Care coordination global measure	*Regional or remote*	3	16.67	6.67	2.08	6.00	2.00
	Metropolitan	15	83.33	5.47	2.23	6.00	2.50
Quality of care global measure	*Regional or remote*	3	16.67	5.67	4.04	8.00	3.50
	Metropolitan	15	83.33	6.07	2.28	6.00	3.50

Ability to take medicine as prescribed

Participants were asked about their ability to take medicines as prescribed. There were no participants that responded that they sometime, never, or rarely took medicines as prescribed (Table 7.18, Figure 7.36).

NMOSD

The majority of participants with NMOSD responded that they took medicine as prescribed all the time (n=11, 61.11%), and seven participants (38.89%) responded that they took medicines as prescribed most of the time.

MOG

The majority of participants with MOG responded that they took medicine as prescribed most of the time(n=6, 75.00%), and two participants (25.00%) responded that they took medicines as prescribed all the time

NMOSD or MOG

Overall, half of the participants with NMOSD or MOG, took medicine as prescribed all of the time, and the other half took medicine as prescribed most of the time.

Table 7.18: Ability to take medicine as prescribed

Ability to take medicine as prescribed	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
Never or Rarely	0	0.00	0	0.00	0	0.00
Sometimes	0	0.00	0	0.00	0	0.00
Most of the time	7	38.89	6	75.00	13	50.00
All of the time	11	61.11	2	25.00	13	50.00

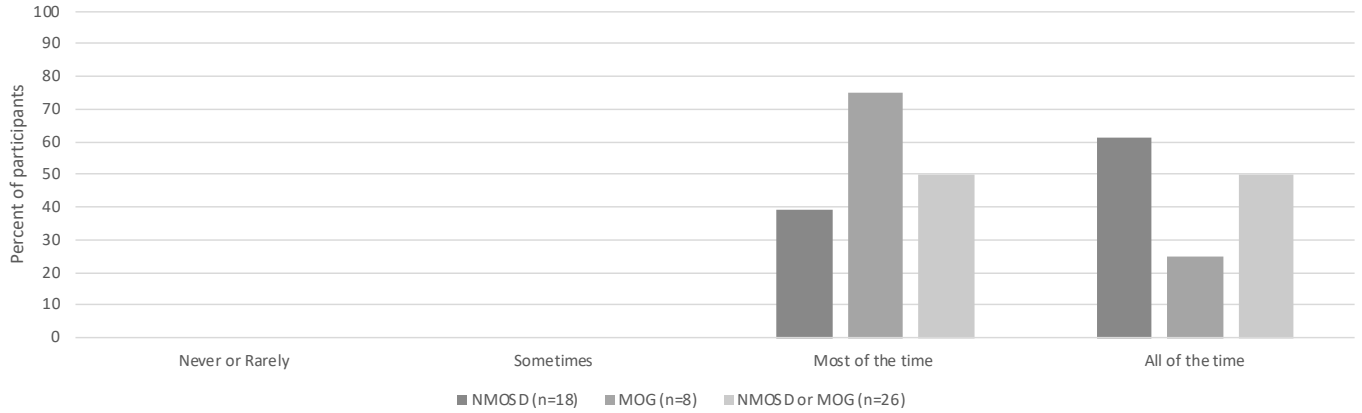

Figure 7.36: Ability to take medicine as prescribed

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. In the general NMOSD population the most common response was that participants and no received any support (n=8, 44.44%). This was followed by receiving support through domestic services (n=7, 38.89%).

Participant describes not receiving any support

No, I haven't received any. Participant NMO_008

No, I haven't had any. Participant NMO_009

None, from nowhere. Participant NMO_003

Participant describes receiving support through domestic services

In December, when it gets reassessed, there's going to be a couple of changes, I would say. Maybe around the home or that kind of stuff, because I can't do as much as I could last year, if that makes any sense. They will help me with my grocery shopping, because I don't want to push the trolley, because I could take something out. Participant NMO_012

Only through NDIS. I get a gardener, I get a cleaner once a fortnight. I get my exercise physiology

through NDIS. NDIS has really been my lifesaver. Participant NMO_004

Yes, I don't know if it falls under community services. Someone comes to my home once a week and prepares the meals for the week. I also have someone come to the home that helps with domestic tasks like she changes the linen on the bed, and she hangs out some washing and stuff like that. Participant NMO_010

Participant describes receiving support for transport

I have access to transport because I had to go quite a way to my physio and if I have to go to hospital appointments and stuff, I can get a taxi. I have funding for that now. I could take a support worker, like when I go to swimming. I've been going to the pool and that's an amazing, because I'm normal in the pool. I can take somebody there if I need. The NDIS gave me the opportunity of getting somebody to help me cook meals for the week. Participant NMO_006

About three years ago, I went through NAME Care type thing. I used to go there and they have their meetings and talks. Virtually, they'd come out, do the housework for me, they would do transport the whole thing, but then I think they were taken over by another company. Participant NMO_013

They have been quite good, but seeing that we've had COVID, I only had one to two weeks of going out shopping and feeling like I was normal again, and then COVID hit. [laughs] I haven't really been able to get out and about, but they have been taking me to my hospital appointments and doctors' appointments. The transport, it's really good having that service there. Participant NMO_012

Participant describes receiving support from a hospital or clinical setting

It will be from my GP. GP and also my psychologist, because I've known my GP for more than 10 years. Participant NMO_001

That was a huge thing. It was just brilliant to be able to see doctors that actually knew about the condition and a whole panel of them, not just one. That was fantastic. Participant NMO_016

Table 7.19: Experience of care and support

Care and support	NMOSD		Fewer relapses		More relapses		Low to moderate fear		Hight to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes not receiving any support	8	44.44	3	33.33	5	55.56	3	37.50	5	50.00	2	22.22	6	66.67
Participant describes receiving support through domestic services	7	38.89	3	33.33	4	44.44	3	37.50	4	40.00	5	55.56	2	22.22
Participant describes receiving support for transport	3	16.67	1	11.11	2	22.22	0	0.00	3	30.00	2	22.22	1	11.11
Participant describes receiving support from a hospital or clinical setting	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	2	22.22	0	0.00

Care and support	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes not receiving any support	8	44.44	5	50.00	3	37.50	3	50.00	5	41.67	3	42.86	5	45.45
Participant describes receiving support through domestic services	7	38.89	5	50.00	2	25.00	3	50.00	4	33.33	3	42.86	4	36.36
Participant describes receiving support for transport	3	16.67	3	30.00	0	0.00	1	16.67	2	16.67	1	28.57	2	18.18
Participant describes receiving support from a hospital or clinical setting	2	11.11	1	10.00	1	12.50	1	16.67	1	8.33	2	28.57	0	0.00

Care and support	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 receiving any support	8	44.44	2	25.00	10	38.46	3	30.00	6	37.50	2	100.00	1	33.33	7	46.67
Participant describes receiving support through domestic services	7	38.89	1	12.50	8	30.77	1	10.00	7	43.75	0	0.00	2	66.67	5	33.33
Participant describes receiving support for transport	3	16.67	1	12.50	4	15.38	1	10.00	3	18.75	0	0.00	1	33.33	2	13.33
Participant describes receiving support from a hospital or clinical setting	2	11.11	1	12.50	3	11.54	2	20.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 7.20: Experience of care and support (Subgroup variations)

Care and support	More frequent	Less frequent
Participant describes not receiving any support	More relapses Good to very good physical function	Fewer relapses Moderate to very poor physical function
Participant describes receiving support through domestic services	Moderate to very poor physical function Trade or high school Mid to low socioeconomic status	Good to very good physical function University

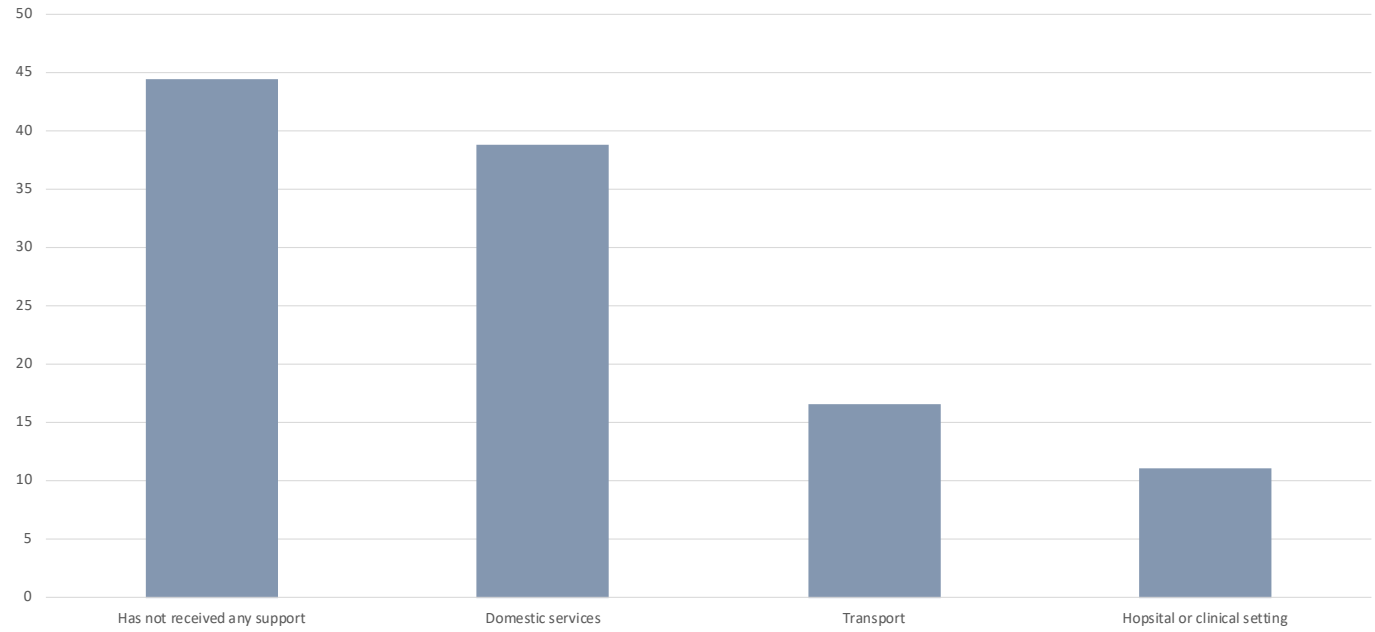

Figure 7.37: Experience of care and support

Section 8

Quality of life

Section 8: Quality of life

Experience of quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 16 participants (88.89%) that described a negative impact on quality of life. The most common themes in relation to having a negative impact on quality of life included emotional strain on family/change in relationship dynamics (n=12, 66.67%), and reduced capacity for physical activity (n=6, 33.33%).

Impact on mental health

In the structured interview, participants were asked whether their mental health had been impacted. There were 15 participants (83.33%) who gave a description suggesting that overall, there was at least some impact on mental health.

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotion and mental health. The most common response from six participants (33.33%) was the importance of physical exercise and this was followed by using mindfulness or meditation (n=5, 27.78%).

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health. The most common way that participants reported managing their health was by being physically active (n=7, 38.89%). There were six participants (33.33%) that described the importance of understanding their limitations and five (27.78%) that described the importance of self care e.g. more rest, support for housework etc.

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 12 participants (66.67%) that described a negative impact on relationships. Where participants described relationships being suffering, this was primarily in relation to their reduced capacity for socialising (n=6, 33.33%).

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Overall, there were 10 participants (55.56%) that felt there was an additional burden. Where participants felt there was an additional burden, this was primarily in relation to extra household duties and responsibilities that their family must take on (n=5, 27.78%), and needing extra assistance to get to appointments (n=5, 27.78%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 14 participants (77.78%) that gave a description suggesting that overall there was at least some cost burden. There were 10 participants (55.56%) that spoke about cost burden in relation to needing to take time off work and nine participants (50.00%) that reported cost burden in relation to the cost of treatments (including repeat scripts).

Overall impact of NMOSD on quality of life

In the online questionnaire, participants were asked to rate the overall impact of having a NMOSD or MOG on quality of life. Quality of life was rated on a Likert scale from one to seven, where one is Life was very distressing and seven is Life was great. The median impact of quality of life from NMOSD was 2.00 (IQR= 1.28), in the "life was distressing" range

Experience of anxiety related to disease progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their condition.

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their condition. Overall, the average fear of progression score for NMOSD participants in this study indicated high levels of anxiety.

The responses to individual questions of the Fear of Progression questionnaire for participants with NMOSD showed that 50% or more participants that were often or very often worried about;disease progression (n=11, 61.11%), reaching professional or personal goals (n=12, 66.67%), relatives being diagnosed with disease (n=9, 50.00%), being able to pursue hobbies (n=15, 83.33%), treatment will damage body (n=11, 61.11%), worried about family if anything happens to them (n=11, 61.11%), and not being able to work (n=9, 50.00%).

Experience of quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 16 participants (88.89%) that described a negative impact on quality of life. The most common themes in relation to having a negative impact on quality of life included emotional strain on family/change in relationship dynamics (n=12, 66.67%), and reduced capacity for physical activity (n=6, 33.33%).

Participant describes an overall negative impact on quality of life

Sure. Pretty much I can't do the things as much, like the housework and all of those things. Looking after my son and enjoying time with him, but having said that, it's just the stress of it as well on the family. I have been sick for quite some time so it's been quite difficult in that regard. Participant NMO_008

Definitely. My quality of life is yes, desperately low, there's not a lot I can do, from a person who was fit, healthy, yes, I did everything and now I can't do 95% of the things I used to do. Participant NMO_009

My quality of life is that I have to now depend on everybody, where before I was very independent. Participant NMO_013

Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics

It has because they're always, when we go anywhere, it's, "Be careful here. Be careful here. There's a bump on the footpath. Watch out you don't fall over." They're always like, "Am I all right?" To see that I haven't fallen over and things like that. Participant NMO_007

Sure. Pretty much I can't do the things as much, like the housework and all of those things. Looking after my son and enjoying time with him, but having said that, it's just the stress of it as well on the family. I have been sick for quite some time so it's been quite difficult in that regard. Participant NMO_008

Yes, absolutely. They don't just fully understand the disease. They were very upset when I first had it and they found it difficult, so I spent a lot of the time trying to console them. A lot of my, including my family, they'll ask me out to places and that and so I can't always go, or I'm not able to do it and I am often saying I'm too tired. I think sometimes that they forget, so they can sometimes stop asking or including you to do things or they get a bit like, "Well yes, she's tired again," and not realise how much the disease can knock you around. Participant NMO_011

Participant describes negative impact on quality of life as a result of reduced capacity for physical activity

Yes. I guess when my partner met me, I was a very different person. I played a lot of high level sport, and that's how we met so going from that to being told that I should have looked at having children at 21 years old. Then obviously losing my job, my mental health was heavily affected, which I guess affected all my family relationships. My partner saw me go from this super-outgoing person who is very active and very optimistic to basically not really wanting to do anything because it could put me at risk and kind of like, what's the point if I'm just going to be in a wheelchair later on, so he had to really work hard to get me, I guess, out of that mindset. Participant NMO_003

My partner and my dad drove me wherever I needed to be. Nowadays- my relationship with some of my friends changed because of the things that we used to do together, I used to be big into mountain biking and stuff which I obviously can't do anymore. Some of those relationships have changed. I used to actively- playing a sport at a high level and then not playing sport at a high level is pretty upsetting. Participant NMO_010

Participant describes negative impact on quality of life due to reduced social interaction

Cancelling things, where maybe just catching up for a coffee or something like that, and then all of a sudden, then that morning, you feel like crap, and you have to cancel. I think I cancelled more than I actually go out. Participant NMO_012

Oh definitely, unfortunately. We've lost quite a few friends because I think we're not the fun couple anymore. The ones that would be the first in the pool and there at the start of the party and there at the end... We used to be fun but we're not as much

fun now. Sometimes we go to parties, we get there and after an hour, NAME PERSON CARED FOR will say, "I feel so bad I need to go home," so we go home. We're not the fun couple anymore. Participant NMOCA_005

Even quality of life like during COVID now, I haven't seen my friends since April. We talk but it's just that the face to face interaction, it sort of put up with, I don't really want to put myself out there and be exposed to COVID just in case, I don't go out as much. If I don't have this condition, I probably would go out like I would normally do and I probably wouldn't care that much. Participant NMO_001

Participant describes a negative impact due to the emotional impact their condition has on them and/or anxiety around prognosis and the future

My partner saw me go from this super-outgoing person who is very active and very optimistic to basically not really wanting to do anything because it could put me at risk and kind of like, what's the point if I'm just going to be in a wheelchair later on, so he had to really work hard to get me, I guess, out of that mindset. I see a psychologist and stuff like that to help me come to terms with it. I'm not as outgoing and stuff anymore because, obviously, I know there's repercussions for me now. Participant NMO_003

This is a mental thing that I still have to adapt to, and that some people think I still need to go and see a psychiatrist. Participant NMO_012

Yes. We have three kids who he hasn't seen in eight weeks. There's, obviously, a lot of fear there about whether he will get to see them grow up, and what disability he might have, and how that would change the way he cares for our kids. Participant NMOCA_002

Participant describes negative impact on quality of life as a result of fatigue

Yes definitely. I feel more tired. I'm not as energetic as I used to be. I used to do everything in the house and I'm not tired. Nowadays I struggle to even go down to the shops and just walk a few shops. Participant NMO_001

I think definitely yes. With my family I guess just possibly feeling a little bit more fatigued than normal because of the loss of vision, psychologically possibly because of the effect of how you might look with one lazy eye. Participant NMO_002

With her quality of life, like I said, she has a lot of fatigue. She doesn't have much interest in anything. Participant NMOCA_006

Participant describes negative impact on quality of life as a result of reduced mobility and/or suffering from a disability

Virtually, the quality of life that I used to play golf, tennis, where now, my quality of life feels-- I'm quite happy to stay at home and just go out on a weekend or something like that. I can't walk and run and do things like that. It's disappointing, but it happens. Participant NMO_013

We used to go on a lot of bush walks and stuff like that if we could, but she can't do that anymore. She can't walk. You can't have a walker in the bush. It's changed. We've sold the bikes, we've sold the kayaks, she sold her golf clubs. It was really hard because we're not going to do that anymore. Participant NMOCA_005

Table 8.1: Experience of quality of life

Impact on quality of life	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	12	66.67	5	55.56	7	77.78	6	75.00	6	60.00	7	77.78	5	55.56
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	6	33.33	4	44.44	2	22.22	2	25.00	4	40.00	3	33.33	3	33.33
Participant describes negative impact on quality of life due to reduced social interaction	4	22.22	2	22.22	2	22.22	3	37.50	1	10.00	1	11.11	3	33.33
Participant describes a negative impact due to the emotional impact their condition has on them and/or anxiety around prognosis and the future	3	16.67	0	0.00	3	33.33	1	12.50	2	20.00	0	0.00	3	33.33
Participant describes negative impact on quality of life as a result of fatigue	3	16.67	1	11.11	2	22.22	3	37.50	0	0.00	2	22.22	1	11.11
Participant describes negative impact on quality of life as a result of reduced mobility and/or suffering from a disability	3	16.67	2	22.22	1	11.11	1	12.50	2	20.00	1	11.11	2	22.22
Participant describes an overall negative impact on quality of life	16	88.89	8	88.89	8	88.89	8	100.00	8	80.00	7	77.78	9	100.00

Impact on quality of life	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	12	66.67	7	70.00	5	62.50	3	50.00	9	75.00	6	85.71	6	54.55
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	6	33.33	4	40.00	2	25.00	1	16.67	5	41.67	3	42.86	3	27.27
Participant describes negative impact on quality of life due to reduced social interaction	4	22.22	2	20.00	2	25.00	2	33.33	2	16.67	2	14.29	2	18.18
Participant describes a negative impact due to the emotional impact their condition has on them and/or anxiety around prognosis and the future	3	16.67	2	20.00	1	12.50	1	16.67	2	16.67	2	28.57	1	9.09
Participant describes negative impact on quality of life as a result of fatigue	3	16.67	1	10.00	2	25.00	1	16.67	2	16.67	2	14.29	1	9.09
Participant describes negative impact on quality of life as a result of reduced mobility and/or suffering from a disability	3	16.67	3	30.00	0	0.00	2	33.33	1	8.33	0	0.00	3	27.27
Participant describes an overall negative impact on quality of life	16	88.89	9	90.00	7	87.50	6	100.00	10	83.33	6	85.71	10	90.91

Impact on quality of life	More frequent	Less frequent
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	More relapses Moderate to very poor physical function Aged 18 to 44	Fewer relapses Good to very good physical function Mid to low socioeconomic status Aged 45 or older
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	Fewer relapses	More relapses Mid to low socioeconomic status
Participant describes an overall negative impact on quality of life	Low to moderate fear Good to very good physical function Mid to low socioeconomic status	Moderate to very poor physical function

Table 8.2: Experience of quality of life (Subgroup variations)

Impact on quality of life	More frequent	Less frequent
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	More relapses Moderate to very poor physical function Aged 18 to 44	Fewer relapses Good to very good physical function Mid to low socioeconomic status Aged 45 or older
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	Fewer relapses	More relapses Mid to low socioeconomic status
Participant describes an overall negative impact on quality of life	Low to moderate fear Good to very good physical function Mid to low socioeconomic status	Moderate to very poor physical function

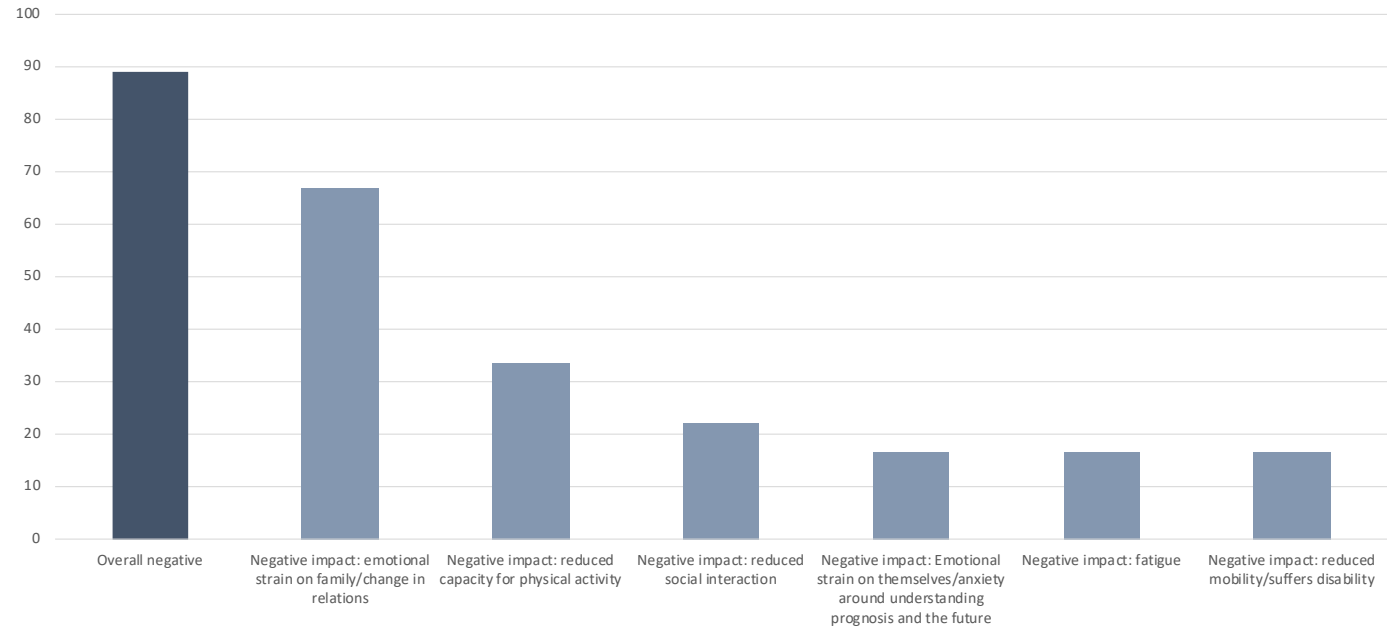

Figure 8.1: Experience of quality of life

Impact on mental health

In the structured interview, participants were asked whether their mental health had been impacted. There were 15 participants (83.33%) who gave a description suggesting that overall, there was at least some impact on mental health.

Participant gives a description suggesting that overall, there was at least some impact on mental health

I think it had a huge impact. Especially like I said due to the fact that one eye tends to move on its own sometimes and that is very mentally and psychologically draining. Also just maybe feel anxious all the time as well just because I just didn't deal with the visual system. Participant NMO_002

When I first got sick with all this, it was horrendous. I would have cried every day and I didn't really know what to do about it. It took a few years for me to accept that. Participant NMO_010

It's quite depressing sometimes, especially when I get to the stage where it spasms up my whole body. I've got to lay on a bed and then my mind's telling me, "You got to get up. You got to get up. You can't lay in bed," type thing. Participant NMO_013

Participant gives a description suggesting that overall, there was no impact on mental health

I don't think it's affected either of us I don't know how it's changing if symptoms become more severe, but I think he's just taking it day by day and just trying to do the best we can, but so far we have been fine. Participant NMOCA_003

I don't think it really has affected me. I'm quite a strong person, so I tend to handle things pretty well. Participant NMOCA_007

Table 8.3: Impact on mental health

Impact on mental health	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant gives a description suggesting that overall, there was at least some impact on mental health	15	83.33	7	77.78	8	88.89	7	87.50	8	80.00	7	77.78	8	88.89
Participant gives a description suggesting that overall, there was no impact on mental health	1	5.56	1	11.11	0	0.00	1	12.50	0	0.00	0	0.00	1	11.11

Impact on mental health	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant gives a description suggesting that overall, there was at least some impact on mental health	15	83.33	8	80.00	7	87.50	5	83.33	10	83.33	7	100.00	8	72.73
Participant gives a description suggesting that overall, there was no impact on mental health	1	5.56	1	10.00	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09

Impact on mental health	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 description suggesting that overall, there was at least some impact on mental health	15	83.33	6	75.00	21	80.77	4	40.00	14	87.50	1	50.00	3	100.00	12	80.00
Participant gives a description suggesting that overall, there was no impact on mental health	1	5.56	1	12.50	2	7.69	4	40.00	1	6.25	0	0.00	0	0.00	1	6.67

Table 8.4: Impact on mental health (Subgroup variations)

Impact on mental health	More frequent	Less frequent
Participant gives a description suggesting that overall, there was at least some impact on mental health	Aged 18 to 44	Aged 45 or older

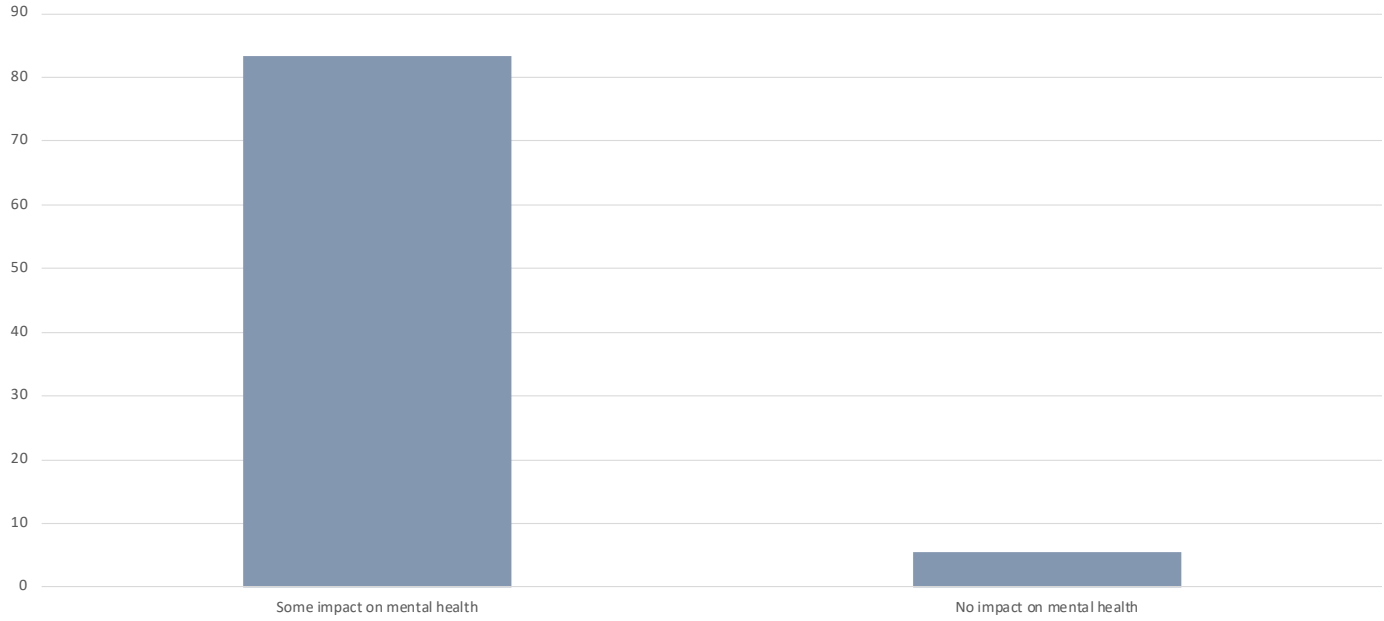

Figure 8.2: Impact on mental health

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotion and mental health. The most common response from six participants (33.33%) was the importance of physical exercise and this was followed by using mindfulness or meditation (n=5, 27.78%).

Participant describes the importance of physical exercise

Exercise and trying to keep my life as normal as I can, when I can. Participant NMO_001

Well, it's really important for me to exercise every day and to get out and walk the dogs no matter how bad I am. If I'm not good, if I'm not having a good day, I take the dogs up to the oval so at least they can get exercise. Being connected with friends, having interests like I do card making and I paint. I've had to reduce my gardening because that's hard to get in on the ground and do gardening.. Participant NMO_004

When I first got sick with all this, it was horrendous. I would have cried every day and I didn't really know what to do about it. It took a few years for me to accept that. Nowadays I do a lot of exercise which actually makes me happy. When I've got an

injury, if I can't exercise, then I don't cope very well with my other symptoms. I go to a great counselling session once a month and actually people with MS. I like going to that, but obviously, I'm quite aware that I don't have MS and it's quite different. Sometimes it's a little isolating in the group where I am the odd one out. Participant NMO_010

Participant describes using mindfulness and/or meditation

I do see psychologists. I do see my psychologist and I do mindfulness meditation. I've been meditating for quite a long time and trying to do something that I enjoy every day. Participant NMO_001

Yes. It makes you mentally tired and mentally frustrated when I can't remember words. When I get tired and my eyesight goes when I get tired and that's frustrating. I go to yoga, not necessarily just for the physical, but for the mental fact of being able to switch off for that hour while I'm there. I do meditation. Participant NMO_006

Yes. I personally contemplate, which is like a meditation. I do that at least once or twice a day for 20 minutes. Participant NMO_016

Participant describes consulting a mental health professional

I do see psychologists. I do see my psychologist and I do mindfulness meditation. I've been meditating for quite a long time and trying to do something that I enjoy every day. Participant NMO_001

I go to a great counselling session once a month and actually people with MS. Participant NMO_010

Well I still see a psychologist and I've just actually seen the doctor to get another session of 20 sessions, I think you can have now. Participant NMOCA_005

Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies

Being connected with friends, having interests like I do card making and I paint. I've had to reduce my gardening because that's hard to get in on the ground and do gardening. Participant NMO_004

The greatest problem is, I don't know whether it's the NMO or with the steroids, I'm very forgetful. I have to write things down, and when either my kids or my wife ask me if I can remember something, I have to write everything down. Participant NMO_007

To look after my mental health, I pretty much just put music on and drown my own thoughts. Participant NMO_012

Participant describes no activities to maintain their mental health though they give a description which suggests it has been affected

It completely effects your mood. Like I have massive mood swings that I can't control, and it's just difficult because everyone's moving forward with their lives around me, and I feel like I'm stuck. Participant NMO_005

I've been very strong, mentally, I always have been, I'm a person who's been able to block things out per se, but deep down I am struggling, I know I am but yes, it's just hard to, yes. Participant NMO_009

As I said, we've been married for 45 years, and the person that you grew up with, and you went through life with, has changed and is reeling from this, so that obviously affects you. It makes me sad, and makes you anxious about the future. Participant NMOCA_004

Participant describes no activities to maintain mental health as their mental health has not been affected

Mentally I'm quite resilient. I get frustrated more than anything at not being able to do some of the things that I used to do or having the stamina to do what I used to do. I liked the very physical labour-intensive thing. Other than that, it doesn't really, you've just got to live with it, if that makes sense. Participant NMO_014

I don't think it really has affected me. I'm quite a strong person, so I tend to handle things pretty well. Participant NMOCA_007

Table 8.5: Regular activities to maintain mental health

Activities to maintain mental health	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes the importance of physical exercise	6	33.33	4	44.44	2	22.22	4	50.00	2	20.00	2	22.22	4	44.44
Participant describes using mindfulness and/or meditation	5	27.78	2	22.22	3	33.33	1	12.50	4	40.00	3	33.33	2	22.22
Participant describes consulting a mental health professional	4	22.22	2	22.22	2	22.22	3	37.50	1	10.00	2	22.22	2	22.22
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	3	16.67	1	11.11	2	22.22	1	12.50	2	20.00	1	11.11	2	22.22
Participant describes no activities to maintain their mental health though they give a description which suggests it has been affected	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	1	11.11	1	11.11
Participant describes no activities to maintain mental health	1	5.56	1	11.11	0	0.00	1	12.50	0	0.00	0	0.00	1	11.11

Activities to maintain mental health	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes the importance of physical exercise	6	33.33	1	10.00	5	62.50	1	16.67	5	41.67	3	42.86	3	27.27
Participant describes using mindfulness and/or meditation	5	27.78	3	30.00	2	25.00	2	33.33	3	25.00	3	14.29	2	18.18
Participant describes consulting a mental health professional	4	22.22	2	20.00	2	25.00	1	16.67	3	25.00	3	42.86	1	9.09
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	3	16.67	2	20.00	1	12.50	1	16.67	2	16.67	0	0.00	3	27.27
Participant describes no activities to maintain their mental health though they give a description which suggests it has been affected	2	11.11	1	10.00	1	12.50	1	16.67	1	8.33	1	14.29	1	9.09
Participant describes no activities to maintain mental health	1	5.56	1	10.00	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09

Activities to maintain mental health	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 the importance of physical exercise	6	33.33	4	50.00	10	38.46	0	0.00	6	37.50	0	0.00	0	0.00	6	40.00
Participant describes using mindfulness and/or meditation	5	27.78	2	25.00	7	26.92	0	0.00	5	31.25	0	0.00	0	0.00	5	33.33
Participant describes consulting a mental health professional	4	22.22	1	12.50	5	19.23	2	20.00	4	25.00	0	0.00	1	33.33	3	20.00
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	3	16.67	2	25.00	5	19.23	1	10.00	2	12.50	1	50.00	1	33.33	2	13.33
Participant describes no activities to maintain their mental health though they give a description which suggests it has been affected	2	11.11	2	25.00	4	15.38	2	20.00	1	6.25	1	50.00	1	33.33	1	6.67
Participant describes no activities to maintain mental health	1	5.56	1	12.50	2	7.69	3	30.00	1	6.25	0	0.00	0	0.00	1	6.67

Table 8.6: Regular activities to maintain mental health (Subgroup variations)

Activities to maintain mental health	More frequent	Less frequent
Participant describes the importance of physical exercise	Fewer relapses Low to moderate fear Good to very good physical function University	More relapses High to very high fear Moderate to very poor physical function Trade or high school Mid to low socioeconomic status
Participant describes using mindfulness and/or meditation	High to very high fear	Low to moderate fear Aged 18 to 44

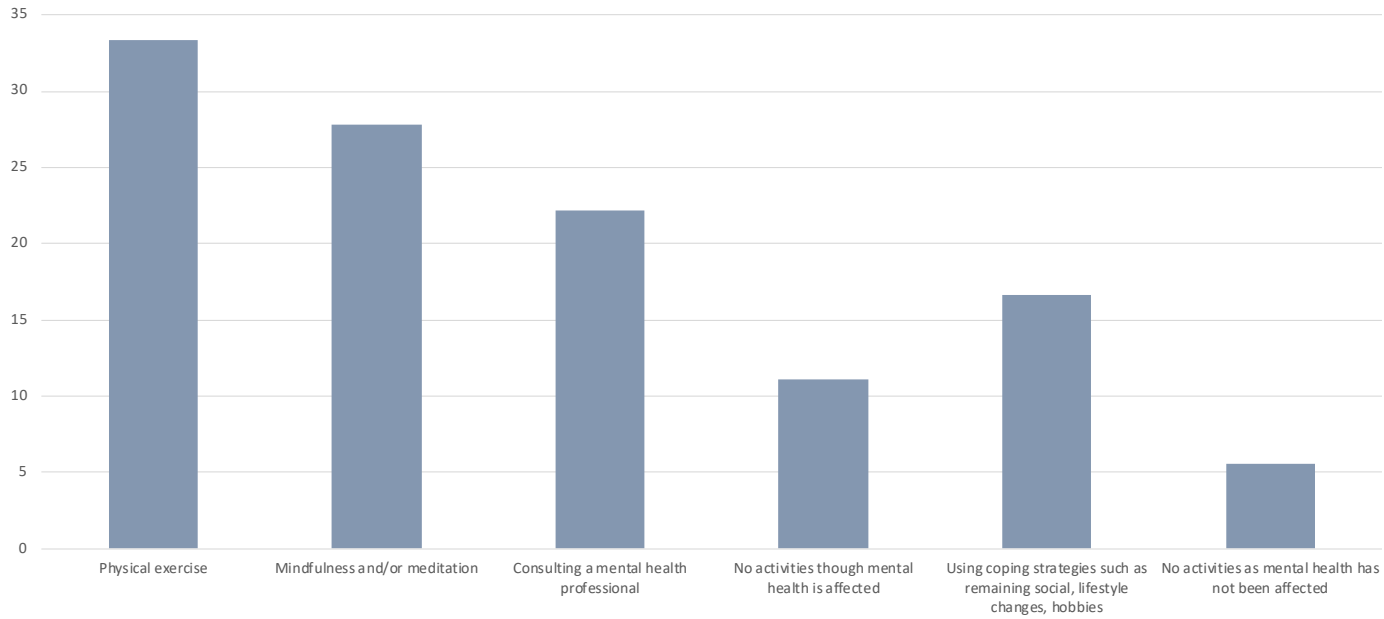

Figure 8.3: Regular activities to maintain mental health

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health. The most common way that participants reported managing their health was by being physically active (n=7, 38.89%). There were six participants (33.33%) that described the importance of understanding their limitations and five (27.78%) that described the importance of self care e.g. more rest, support for housework etc.

In relation to subgroup variations, participants in the subgroups *Aged 45 or older* (27.27%), *Trade or high school* (20.00%), *Mid to low socioeconomic status* (16.67%),and *Family and carers* (10.00%) described staying physically active less frequently than the general NMOSD population (38.89%), while those in the subgroups *Low to moderate fear* (50.00%) *Aged 18 to 44* (57.14%), *University* (62.50%) and *Higher socioeconomic status* (50.00%) described this more frequently.

Participants in the subgroup *Mid to low socioeconomic status* (16.67%) described the importance of understanding their limitations less frequently than the general NMOSD population (33.33%).

Participants in the subgroup *Family and carers* (10.00%) describes the importance of self care less frequently than the general NMOSD population (27.78%).

Participant describes being physically active

I think swimming, so pools opening up here in LOCATION METROPOLITAN would be great because I find when I'm in water, it's much better. Being able to access the gym and having the machines to help strengthen my body is good, being able to get outdoors and walk, connecting with people, making sure that you're not on your own day in day out.. Participant NMO_004

I go to the gym. I try to go to the gym every day, but some days I guess I can't. I just try and live a normal life, and I just try and disregard that I have this condition basically, yes. Participant NMO_003

Well, for me, I meditate, I do yoga, and I go for a walk, and I feel like this is—I see a massive difference, massively changed my life as well. I'm like more calm and I'm more okay with things, so I don't really blow up and I try my best to-- I don't know, be normal. Participant NMO_005

Participant describes the importance of understanding their limitations

I keep a diary and I have to write lists so I don't forget things. I get pleasure out of my dogs, got a couple of dogs. I share them with my brother, he and I share them. If I'm not particularly well or anything like that, he can take them. I try to, when it's cooler, try to go down to the river and take the dogs down there. That gives me enjoyment but I don't venture too far from home because of the heat, mostly. Also, I've got other things to do apart from keeping the home, like of an evening, I need to go out and water garden and do things like that. Participant NMO_011

I have to manage my body, so I have to listen to what my body says. If I push my body too much, it will get worse. Participant NMO_013

I think I have to have insight to when I'm fatigued and I have to stop. That's taken time to learn to stop and rest for a bit, and I'm still learning to do that. I'm pretty bad at that. Participant NMO_017

Participant describes the importance of self care e.g. more rest, support for housework etc.

Make sure I'm well-rested, that's the main thing. I've got to sleep and just plan my day so I don't get too exhausted. Participant NMO_008

Pretty much, if I want to do something in particular, I might just go down the street and just have a bit of a look at the shops. I will make sure that I lay down and just rest, not be stressed, or anything like that, but just rest on the lounge. I don't have to sleep but that's the only way. I've got to really rest every bit of my body, to know, "Okay, I've got to find that energy to reach out to be able to go and do that." That's the only way that I can function. If I know something's coming up that I have to go to, but sometimes it doesn't always help. Participant NMO_012

Sleep, when my body tells me I need to, regular massage, whether it be via massage person or in my massage chair just the compression on my hands, my legs and things like that, just really

helps. Just doing the smaller things that I know I can do and enjoy doing. Participant NMO_014

Participant describes the importance of complying with treatment

Well, it's about physio, that's pretty much I do that once or twice a week, obviously I got to do the medication the exact times each day, that was critical, other than that, it's just about the mental attitude and that's being positive and trying to keep pushing forward and doing what I can do each day.. Participant NMO_009

Yes, physio, the ongoing Rituximab. Participant NMOCA_002

I would just make sure that he takes his medication. Participant NMOCA_007

Table 8.7: Regular activities to maintain health

Regular activities to maintain health	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very goo physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes being physically active	7	38.89	3	33.33	4	44.44	4	50.00	3	30.00	1	11.11	6	66.67
Participant describes the importance of understanding their limitations	6	33.33	3	33.33	3	33.33	3	37.50	3	30.00	3	33.33	3	33.33
Participant describes the importance of self care e.g. more rest, support for housework etc.	5	27.78	3	33.33	2	22.22	3	37.50	2	20.00	1	11.11	4	44.44
Participant describes the importance of complying with treatment	3	16.67	2	22.22	1	11.11	1	12.50	2	20.00	2	22.22	1	11.11

Regular activities to maintain health	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes being physically active	7	38.89	2	20.00	5	62.50	1	16.67	6	50.00	4	57.14	3	27.27
Participant describes the importance of understanding their limitations	6	33.33	4	40.00	2	25.00	1	16.67	5	41.67	2	28.57	4	36.36
Participant describes the importance of self care e.g. more rest, support for housework etc.	5	27.78	3	30.00	2	25.00	2	33.33	3	25.00	1	28.57	4	36.36
Participant describes the importance of complying with treatment	3	16.67	2	20.00	1	12.50	2	33.33	1	8.33	2	28.57	1	9.09

Regular activities to maintain health	NMOSD		MOG		NMOSD and MOG		Family and carers		Female		Male		Regional or remote		Metropolitan	
	n=18	%	n=8	%	n=26	%	n=10	%	n=16	%	n=2	%	n=3	%	n=11	%
Participant describes being physically active	7	38.89	2	25.00	9	34.62	1	10.00	7	43.75	0	0.00	0	0.00	7	46.67
Participant describes the importance of understanding their limitations	6	33.33	4	50.00	10	38.46	4	40.00	6	37.50	0	0.00	1	33.33	5	33.33
Participant describes the importance of self care e.g. more rest, support for housework etc.	5	27.78	4	50.00	9	34.62	1	10.00	5	31.25	0	0.00	1	33.33	4	26.67
Participant describes the importance of complying with treatment	3	16.67	1	12.50	4	15.38	3	30.00	2	12.50	1	50.00	1	33.33	2	13.33

Table 8.8: Regular activities to maintain health (Subgroup variations)

Regular activities to maintain health	More frequent	Less frequent
Participant describes being physically active	Low to moderate fear Good to very good physical function University Higher socioeconomic status Aged 18 to 44	Moderate to very poor physical function Trade or high school Mid to low socioeconomic status Aged 45 or older
Participant describes the importance of understanding their limitations	-	Mid to low socioeconomic status
Participant describes the importance of self care e.g. more rest, support for housework etc.	Good to very good physical function	Moderate to very poor physical function

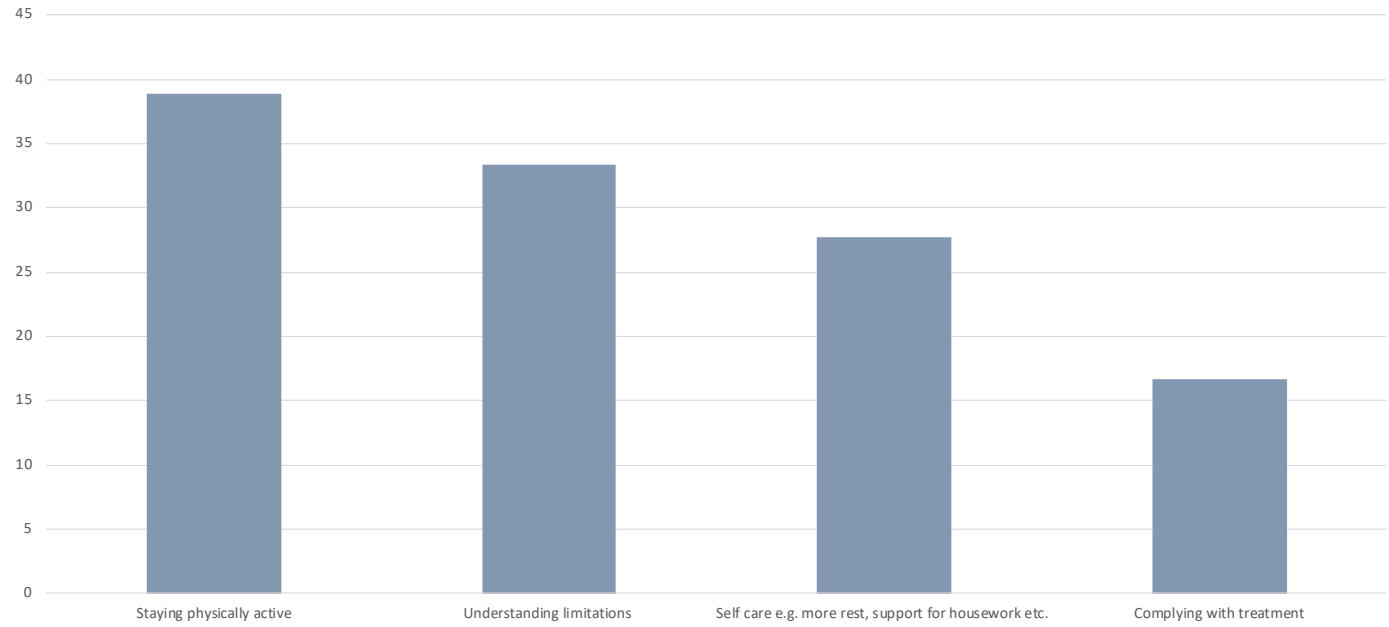

Figure 8.4: Regular activities to maintain health

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 12 participants (66.67%) that described a negative impact on relationships.

Participant describes a negative impact on relationships

Yes, definitely. I've lost friends over it because people don't understand it. I lost my husband. It definitely affects relationships and it's definitely affected the quality of my life. Participant NMO_004

That's why I don't see my friends that much. I haven't seen them since COVID and I don't even really see my extended family either because they live in LOCATION METROPOLITAN where the clusters are. Participant NMO_001

I think so. Some friends, they just don't want to hear. If you just need to get something off your chest, or whatever, that's something about you, what you're feeling, some people just go, "All right. Here she goes again." It's that brush off. Now, I pretty much don't say too much at all. Unless it's the real, real close friends, or my husband. Participant NMO_012

Participant describes no impact on relationships

No. Participant NMO_002

No. Participant NMO_015

No, not at all. My friends know and they're 100% supportive. They regularly ask, "How are things going? Participant MOG_007

Participant describes a positive impact on relationships

I've met new friends, which is amazing. Relationships, yes, I think the whole episode when it was initially first happening opened a lot of people to me. I think I've got better relationships and the ones that I do have now. Participant NMO_006

No. I think it's made it stronger. I think it's made me a stronger person, and I think it's made our relationships stronger, and I think you have a different outlook about life, and about any worries that were insignificant. I just let it go now, because it's not worth it. Participant NMO_017

I think more good than bad. Everybody has been very supportive including at his work. Participant NMOCA_003

Table 8.9: Impact on relationships

Impact on relationships	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes a negative impact on relationships	12	66.67	6	66.67	6	66.67	5	62.50	7	70.00	6	66.67	6	66.67
Participant describes no impact on relationships	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	0	0.00	2	22.22
Participant describes a positive impact on relationships	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	1	11.11	1	11.11

Impact on relationships	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes a negative impact on relationships	12	66.67	8	80.00	4	50.00	4	66.67	8	66.67	5	71.43	7	63.64
Participant describes no impact on relationships	2	11.11	0	0.00	2	25.00	1	16.67	1	8.33	1	14.29	1	9.09
Participant describes a positive impact on relationships	2	11.11	1	10.00	1	12.50	0	0.00	2	16.67	1	14.29	1	9.09

Impact on relationships	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 negative impact on relationships	12	66.67	3	37.50	15	57.69	3	30.00	10	62.50	2	100.00	2	66.67	10	66.67
Participant describes no impact on relationships	2	11.11	3	37.50	5	19.23	2	20.00	2	12.50	0	0.00	0	0.00	2	13.33
Participant describes a positive impact on relationships	2	11.11	1	12.50	3	11.54	2	20.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 8.10: Impact on relationships (Subgroup variations)

Impact on relationships	More frequent	Less frequent
Participant describes relationships suffering due to their reduced capacity for socialising	Good to very good physical function	Moderate to very poor physical function Mid to low socioeconomic status

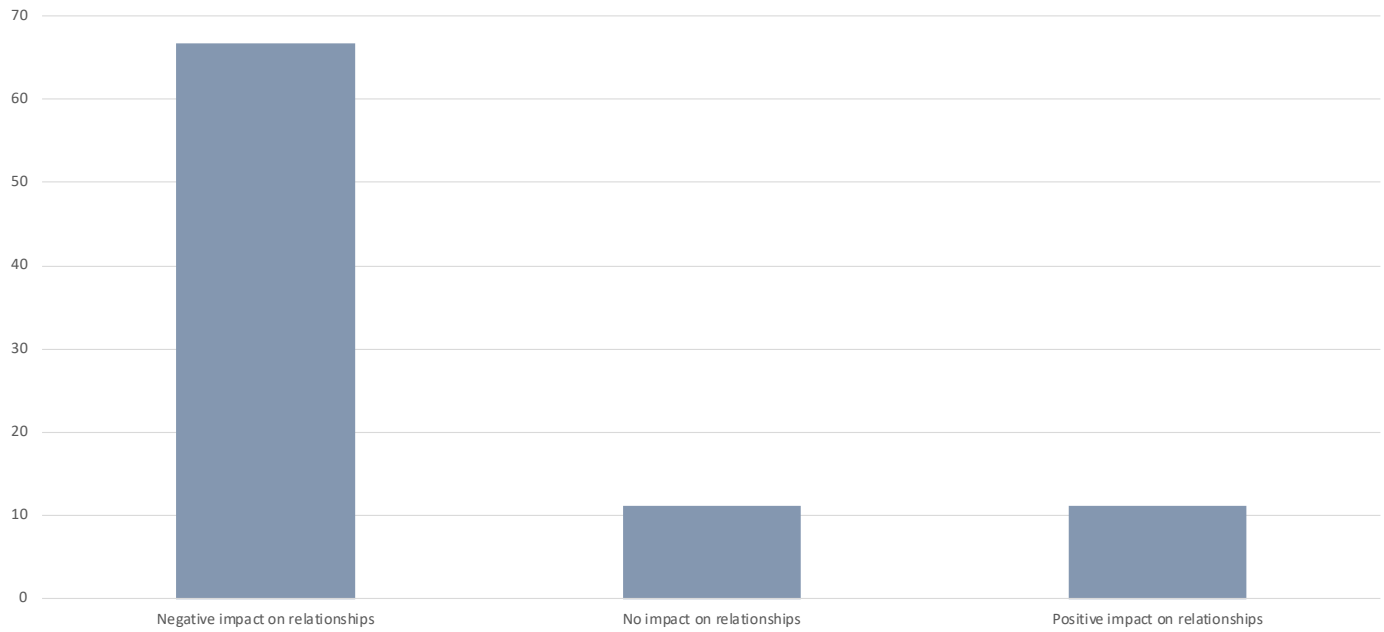

Figure 8.5: Impact on relationships

Impact on relationships: reasons

Where participants described relationships being suffering, this was primarily in relation to their reduced capacity for socialising (n=6, 33.33%).

In relation to subgroup variations, participants in the subgroup *Mid to low socioeconomic status* (16.67%) described relationships suffering due to their reduced capacity for socialising less frequently than the general NMOSD population (33.33%). No participants in the subgroup *Family and carers* (0.00%) described this.

Participant describes relationships suffering due to their reduced capacity for socialising

Yes. I just think my family don't really understand my condition and neither did my friends. My friends don't understand that I can't do everything that I used to be able to do and don't understand the fatigue and stuff because I guess they'd never experienced it before. I don't go out and do a lot of social events just because I know that I'll pay for it the next day or the next few days. Participant NMO_003

My family, yes, a little bit, I used to spend a lot of time with my nephews and nieces looking after them, and now I just don't have the energy to do that. I think my family understands that I don't have the energy, that I'm not just avoiding them or whatever. Participant NMO_010

Yes, but that's my fault. If that makes sense. I just don't jump in the car and travel and do stuff like I used to. Participant NMO_014

Participant describes no impact on relationships (general)

No. Participant NMO_002

No. Participant NMO_015

Participant describes relationships with family being strengthened

No. I think it's made it stronger. I think it's made me a stronger person, and I think it's made our relationships stronger, and I think you have a different outlook about life, and about any worries that were insignificant. I just let it go now, because it's not worth it. Participant NMO_017

I think more good than bad. Everybody has been very supportive including at his work. Participant NMOCA_003

I made a decision in the beginning that if people didn't make an effort then-- it made me choose my friends and my relationships more because life's too short to fight for something. If they're not willing to fight and want to put into it, then I won't, because I only have so much energy. There's only so many people I'll spend it on. Participant NMO_006

Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships

I think so. Some friends, they just don't want to hear. If you just need to get something off your chest, or whatever, that's something about you, what you're feeling, some people just go, "All right. Here she goes again." It's that brush off. Now, I pretty much don't say too much at all. Unless it's the real, real close friends, or my husband. Participant NMO_012

It has with family. I'm talking about my husband here. All of our family is back in LOCATION OVERSEAS so there's nobody here. Some friends I think have distanced themselves. [chuckles]. Participant NMOCA_006

100%, yes. 100%. Like I say, people used to go bushwalking or invite us all and have a party. They thought, "We didn't invite you because we thought NAME PERSON CARED FOR might not be up to it." [chuckles] Well, let her say, "No," that we don't want to come or whatever, but still invite us. Participant NMOCA_005

Table 8.11: Impact on relationships: reasons

Impact on relationships	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very goo physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes a negative impact on relationships	12	66.67	6	66.67	6	66.67	5	62.50	7	70.00	6	66.67	6	66.67
Participant describes no impact on relationships	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	0	0.00	2	22.22
Participant describes a positive impact on relationships	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	1	11.11	1	11.11

Impact on relationships	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes a negative impact on relationships	12	66.67	8	80.00	4	50.00	4	66.67	8	66.67	5	71.43	7	63.64
Participant describes no impact on relationships	2	11.11	0	0.00	2	25.00	1	16.67	1	8.33	1	14.29	1	9.09
Participant describes a positive impact on relationships	2	11.11	1	10.00	1	12.50	0	0.00	2	16.67	1	14.29	1	9.09

Impact on relationships	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 negative impact on relationships	12	66.67	3	37.50	15	57.69	3	30.00	10	62.50	2	100.00	2	66.67	10	66.67
Participant describes no impact on relationships	2	11.11	3	37.50	5	19.23	2	20.00	2	12.50	0	0.00	0	0.00	2	13.33
Participant describes a positive impact on relationships	2	11.11	1	12.50	3	11.54	2	20.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 8.12: Impact on relationships: reasons (Subgroup variations)

Impact on relationships	More frequent	Less frequent
Participant describes a negative impact on relationships	*Trade or high school*	*University*

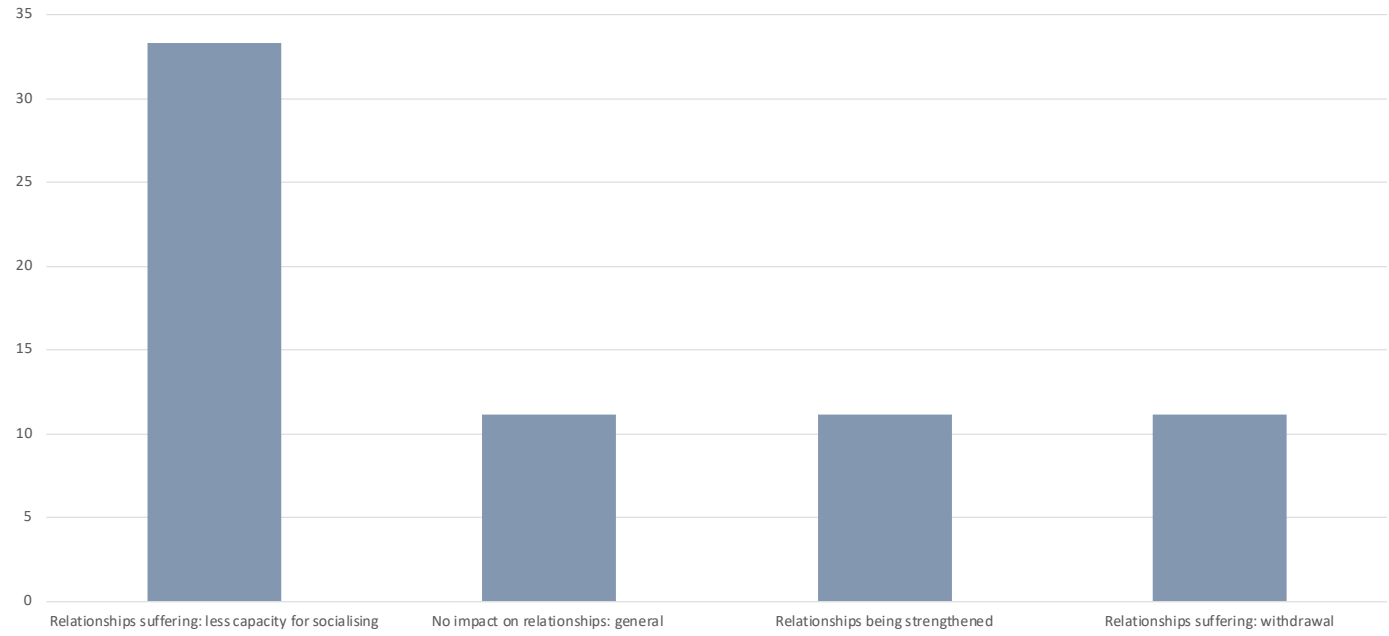

Figure 8.6: Impact on relationships: reasons

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Overall, there were 10 participants (55.56%) that felt there was an additional burden. Where participants felt there was an additional burden, this was primarily in relation to extra household duties and responsibilities that their family must take on (n=5, 27.78%), and needing extra assistance to get to appointments (n=5, 27.78%).

Participant gives a description suggesting that overall, there was a burden on their family

Yes, 100% as well. Because I can't drive, I'm very dependent on people around me. For example, when I had the plasma exchange, I had a catheter so I had to have someone at home to help me wash my hand. Participant NMO_005

I think at the time of the attacks, it was a burden for them. Now that my condition has stabilised, that's not so much for me, but I definitely know for other people it is a huge burden. They have to be, yes. Family members and carers, definitely. I know, with my own children that are now adults, they had to cook the meals for me or they might have had to do more housework or they stepped up when I couldn't, and they were also studying. Participant NMO_004

Yes, 100% as well. Because I can't drive, I'm very dependent on people around me. For example, when I had the plasma exchange, I had a catheter so I had to have someone at home to help me wash my hand. Also, one of my side effects was I've got kind of like severe warts under my feet, and nothing seemed to help them, so I've had to have chemotherapy injections under my feet. I can't walk-- Everybody helped me, my parents, my brother, and his fiancé, without them, I don't know what I would do.. Participant NMO_005

Participant gives a description suggesting that overall, there was not a burden on their family

No, it's just fine. Participant NMO_002

That's an interesting question. It's a different direction for our family, there's no doubt about that. As far as a burden, it's the cards we've been dealt, so we make the best of that. No one is annoyed at providing any assistance with that.. Participant NMOCA_004

No. I don't see it as a burden. Participant NMOCA_006

Participant describes extra household duties and responsibilities that their family must take on

They have to be, yes. Family members and carers, definitely. I know, with my own children that are now adults, they had to cook the meals for me or they might have had to do more housework or they stepped up when I couldn't, and they were also studying. Participant NMO_004

Yes. Yes [chuckles] yes, my husband has to do most things. He's doing things in the garden now and I can't go in the garden. If it's warm and sunny, I can't go out then, because the heat affects me, so I can't go outside. Participant NMO_006

With my husband, he's doing a lot more for me and my son. Obviously, the impact on him as well because he doesn't like seeing mum tired and not well. Participant NMO_008

Participant describes extra assistance needed getting to appointments

Yes, 100% as well. Because I can't drive, I'm very dependent on people around me. For example, when I had the plasma exchange, I had a catheter so I had to have someone at home to help me wash my hand. Participant NMO_005

It is. Yes. It's probably a burden on my husband, because when I have different treatments, obviously you can't drive after treatments or different things. He has to-- because he still works. Participant NMO_013

I didn't need help showering and stuff, or anything like that, but just going to appointments, getting to my treatments. I relied on my family a lot for that. Participant NMO_017

Table 8.13: Burden on family

Burden on family	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes extra household duties and responsibilities that their family must take on	5	27.78	2	22.22	3	33.33	3	37.50	2	20.00	2	22.22	3	33.33
Participant describes extra assistance needed getting to appointments	5	27.78	3	33.33	2	22.22	2	25.00	3	30.00	1	11.11	4	44.44
Participant describes their condition not being a burden in general (No specific examples)	2	11.11	1	11.11	1	11.11	2	25.00	0	0.00	0	0.00	2	22.22
Participant describes their condition being a burden in general (No specific examples)	2	11.11	1	11.11	1	11.11	0	0.00	2	20.00	2	22.22	0	0.00
Participant gives a description suggesting that overall, there was a burden on their family	10	55.56	3	33.33	7	77.78	3	37.50	7	70.00	7	77.78	3	33.33
Participant gives a description suggesting that overall, there was not a burden on their family	2	11.11	1	11.11	1	11.11	2	25.00	0	0.00	0	0.00	2	22.22

Burden on family	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes extra household duties and responsibilities that their family must take on	5	27.78	2	20.00	3	37.50	0	0.00	5	41.67	2	28.57	3	27.27
Participant describes extra assistance needed getting to appointments	5	27.78	2	20.00	3	37.50	2	33.33	3	25.00	1	14.29	4	36.36
Participant describes their condition not being a burden in general (No specific examples)	2	11.11	1	10.00	1	12.50	1	16.67	1	8.33	1	14.29	1	9.09
Participant describes their condition being a burden in general (No specific examples)	2	11.11	2	20.00	0	0.00	2	33.33	0	0.00	1	14.29	1	9.09
Participant gives a description suggesting that overall, there was a burden on their family	10	55.56	8	80.00	2	25.00	4	66.67	6	50.00	3	14.29	7	63.64
Participant gives a description suggesting that overall, there was not a burden on their family	2	11.11	1	10.00	1	12.50	1	16.67	1	8.33	1	42.86	1	9.09

Burden on family	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 extra household duties and responsibilities that their family must take on	5	27.78	0	0.00	5	19.23	1	10.00	5	31.25	0	0.00	0	0.00	5	33.33
Participant describes extra assistance needed getting to appointments	5	27.78	0	0.00	5	19.23	0	0.00	5	31.25	0	0.00	1	33.33	4	26.67
Participant describes their condition not being a burden in general (No specific examples)	2	11.11	2	25.00	4	15.38	4	40.00	2	12.50	0	0.00	0	0.00	2	13.33
Participant describes their condition being a burden in general (No specific examples)	2	11.11	2	25.00	4	15.38	3	30.00	1	6.25	1	50.00	1	33.33	1	6.67
Participant gives a description suggesting that overall, there was a burden on their family	10	55.56	6	75.00	16	61.54	3	30.00	8	50.00	2	100.00	3	100.00	7	46.67
Participant gives a description suggesting that overall, there was not a burden on their family	2	11.11	2	25.00	4	15.38	5	50.00	2	12.50	0	0.00	0	0.00	2	13.33

Table 8.14: Burden on family (Subgroup variations)

Burden on family	More frequent	Less frequent
Participant describes extra household duties and responsibilities that their family must take on	Higher socioeconomic status	Mid to low socioeconomic status
Participant describes extra assistance needed getting to appointments	Good to very good physical function	Moderate to very poor physical function Aged 18 to 44
Participant gives a description suggesting that overall, there was a burden on their family	More relapses High to very high fear Moderate to very poor physical function Trade or high school Mid to low socioeconomic status	Fewer relapses Low to moderate fear Good to very good physical function University Aged 18 to 44

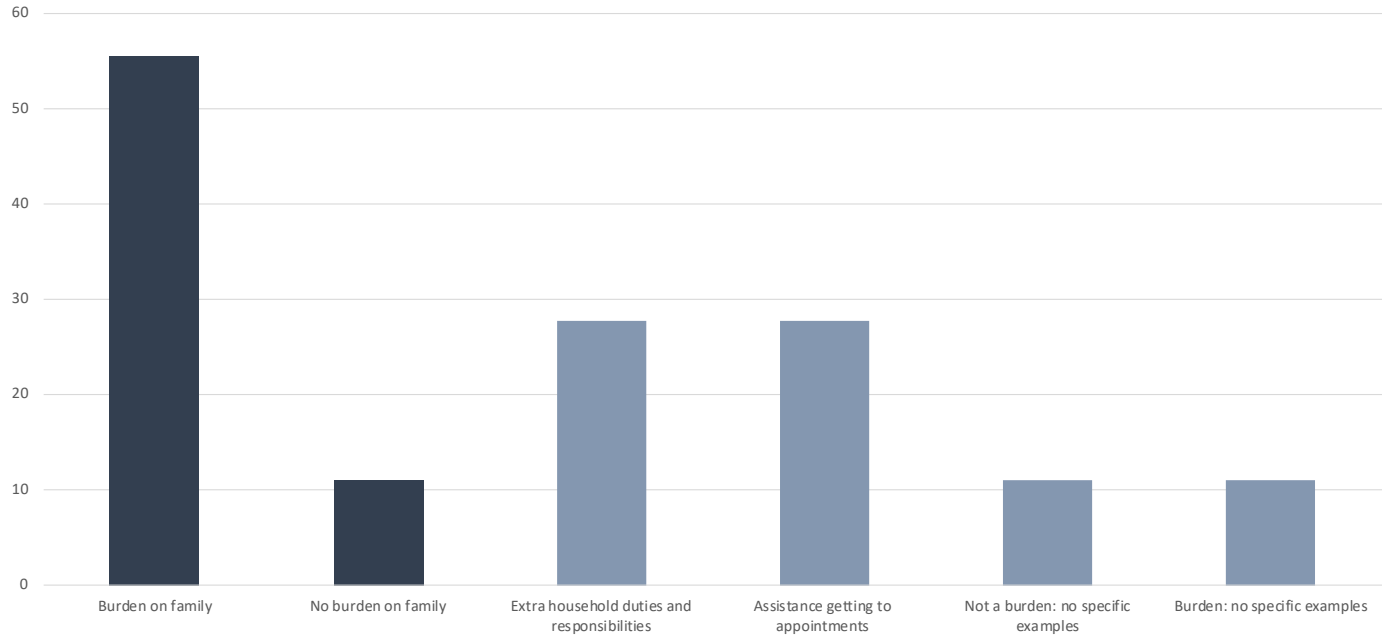

Figure 8.7: Burden on family

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 14 participants (77.78%) that gave a description suggesting that overall there was at least some cost burden. There were 10 participants (55.56%) that spoke about cost burden in relation to needing to take time off work and nine participants (50.00%) that reported cost burden in relation to the cost of treatments (including repeat scripts).

Participant gives a description suggesting that overall, there was at least some cost burden

Obviously, I lost my job, my career, so that was pretty big financial burden. Participant NMO_003

Oh. I've lost my job. I don't work now. That's had a huge impact on our lives. My husband is working two jobs to keep the house, the mortgage and all those kinds of things. Participant NMO_006

Yes, it was huge. When I was first referred for MRI, they cost about $1,400 and because I hadn't been referred by a neurologist yet, I had to pay those upfront. Participant NMO_010

Participant gives a description suggesting that overall, there was no cost burden

Everything I've gone through the public system, I have got private cover, so I do sign for them to claim on my medical funds. All the MRIs, everything, its all been for free. Participant NMO_007

I've really had no cost associated with it because I've gone public the whole time. Even my MRIs are all done at a hospital, I don't pay for them. Participant NMO_017

I think we have been fairly lucky in a sense, apart from the first assessment before he was diagnosed and everything has been pretty much paid for. The treatment is free, blood test only because there's this CD19 component. You'd have to go from LOCATION METROPOLITAN to LOCATION METROPOLITAN so that there wasn't extra cost for them. Participant NMOCA_003

Participant describes a cost burden in relation to needing to take time off work

The cost of my husband having a lot of time off work for me to go to my hospital appointment. Participant NMO_012

I actually had to give up work and I tried to work part-time but I couldn't. She needed me a lot more and I couldn't cope with working as well as looking after NAME PERSON CARED FOR. Participant NMO_016

Oh. I've lost my job. I don't work now. That's had a huge impact on our lives. My husband is working two jobs to keep the house, the mortgage and all those kinds of things. Participant NMO_006

Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)

I was just sent to the neuro physio and I didn't have to pay for that, but all the medications and everything I had to pay for. Participant NMO_010

As well as my financial situation changed because I was no longer able to work. Then you've got the cost of your immunosuppression every month. It's not a huge cost, but over several years, it adds up. Luckily, all my yearly MRIs and tests are all put through the public health system. When I've been to hospital, it's all been covered. That part of it isn't there, but it's the extra huge cost to my superannuation and my working life and cost of pharmaceutical stuff, having to constantly be on drugs, that it is the expense. Participant NMO_004

Participant describes a cost burden in relation to a family member needing to take time off work

The cost of my husband having a lot of time off work for me to go to my hospital appointment. Participant NMO_012

Well my husband will have to take some time off work when I got sick. I don't work so that helped, it didn't make a difference with me but obviously, my husband will have to take on much, well because we've got a child as well. He will have to do school duties and stuff like that. Just the time because scan to scan, you just have to take time out. Participant NMO_001

Well, the human cost is huge, because I remember my son, every time I had an attack at school, and I'd be in the corridor not being able to walk down the car and they'd call an ambulance. Because my son was working locally, he was the one that dropped his tools, I missed out on work, he missed out on work. Participant NMO_004

Participant describes no cost burden and that nearly everything was paid for through the health system

Everything I've gone through the public system, I have got private cover, so I do sign for them to claim on my medical funds. All the MRIs, everything, its all been for free. Participant NMO_007

I've really had no cost associated with it because I've gone public the whole time. Even my MRIs are all done at a hospital, I don't pay for them. Participant NMO_017

Table 8.15: Cost considerations

Cost considerations	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes a cost burden in relation to needing to take time off work	10	55.56	4	44.44	6	66.67	4	50.00	6	60.00	3	33.33	7	77.78
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	9	50.00	4	44.44	5	55.56	5	62.50	4	40.00	4	44.44	5	55.56
Participant describes a cost burden in relation to a family member needing to take time off work	3	16.67	2	22.22	1	11.11	2	25.00	1	10.00	2	22.22	1	11.11
Participant describes no cost burden and that nearly everything was paid for through the health system	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	1	11.11	1	11.11
Participant gives a description suggesting that overall, there was at least some cost burden	14	77.78	7	77.78	7	77.78	6	75.00	8	80.00	6	66.67	8	88.89
Participant gives a description suggesting that overall, there was no cost burden	3	16.67	1	11.11	2	22.22	2	25.00	1	10.00	2	22.22	1	11.11

Cost considerations	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes a cost burden in relation to needing to take time off work	10	55.56	6	60.00	4	50.00	4	66.67	6	50.00	5	71.43	5	45.45
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	9	50.00	5	50.00	4	50.00	3	50.00	6	50.00	6	85.71	3	27.27
Participant describes a cost burden in relation to a family member needing to take time off work	3	16.67	1	10.00	2	25.00	1	16.67	2	16.67	1	14.29	2	18.18
Participant describes no cost burden and that nearly everything was paid for through the health system	2	11.11	1	10.00	1	12.50	0	0.00	2	16.67	0	0.00	2	18.18
Participant gives a description suggesting that overall, there was at least some cost burden	14	77.78	8	80.00	6	75.00	5	83.33	9	75.00	7	100.00	7	63.64
Participant gives a description suggesting that overall, there was no cost burden	3	16.67	2	20.00	1	12.50	1	16.67	2	16.67	0	0.00	3	27.27

Cost considerations	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 cost burden in relation to needing to take time off work	10	55.56	6	75.00	16	61.54	2	20.00	10	62.50	0	0.00	1	33.33	9	60.00
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	9	50.00	2	25.00	11	42.31	1	10.00	8	50.00	1	50.00	1	33.33	8	53.33
Participant describes a cost burden in relation to a family member needing to take time off work	3	16.67	0	0.00	3	11.54	4	40.00	3	18.75	0	0.00	1	33.33	2	13.33
Participant describes no cost burden and that nearly everything was paid for through the health system	2	11.11	1	12.50	3	11.54	2	20.00	1	6.25	1	50.00	0	0.00	2	13.33
Participant gives a description suggesting that overall, there was at least some cost burden	14	77.78	7	87.50	21	80.77	7	70.00	13	81.25	1	50.00	2	66.67	12	80.00
Participant gives a description suggesting that overall, there was no cost burden	3	16.67	1	12.50	4	15.38	2	20.00	2	12.50	1	50.00	1	33.33	2	13.33

Table 8.16: Cost considerations (Subgroup variations)

Cost considerations	More frequent	Less frequent
Participant describes a cost burden in relation to needing to take time off work	More relapses Moderate to very poor physical function Mid to low socioeconomic status Aged 18 to 44	Fewer relapses Moderate to very poor physical function Aged 45 or older
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	Low to moderate fear Aged 18 to 44	High to very high fear Aged 45 or older
Participant gives a description suggesting that overall, there was at least some cost burden	Good to very good physical function Aged 18 to 44	Moderate to very poor physical function Aged 45 or older

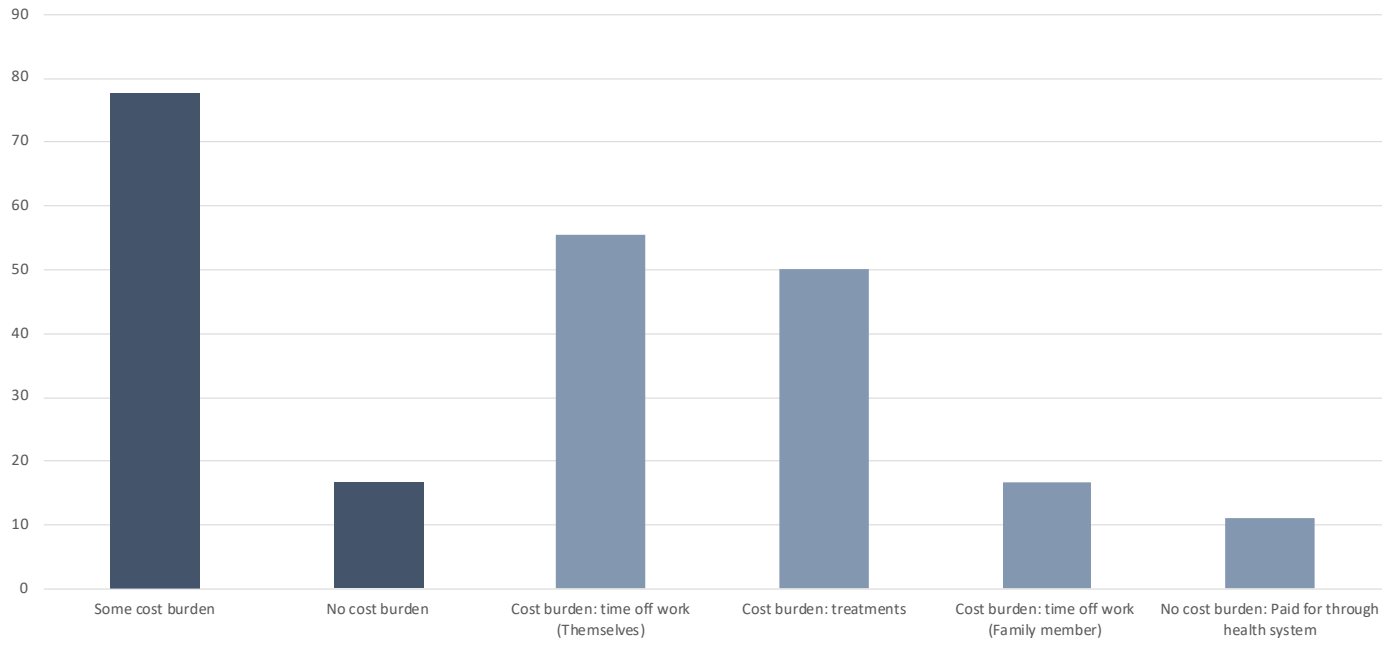

Figure 8.8: Cost considerations

Overall impact of NMOSD on quality of life

In the online questionnaire, participants were asked to rate the overall impact of having a NMOSD or MOG on quality of life. Quality of life was rated on a Likert scale from one to seven, where one is Life was very distressing and seven is Life was great (Table 8.17, Figure 8.9).

NMOSD

The median impact of quality of life from NMOSD was 2.00 (IQR= 1.28), in the "life was distressing" range.

MOG

The median impact of quality of life from MOG was 3.00 (IQR= 0.25), in the "life was a little distressing" range

NMOSD or MOG

The median impact of quality of life from NMOSD or MOG was 2.50 (IQR= 0.27), in the "life was distressing" to "life was a little distressing" range

Table 8.17: Overall impact of NMOSD on quality of life

Impact of condition on quality of life	Participants with NMOSD		Participants with MOG		Participants with NMO or MOG	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent
1 Life is/was very distressing	4	22.22	0	0.00	4	15.38
2 Life is/was distressing	7	38.89	2	25.00	9	34.62
3 Life is/was a little distressing	1	5.56	6	75.00	7	26.92
4 Life is/was average	4	22.22	0	0.00	4	15.38
5 Life is/was good	1	5.56	0	0.00	1	3.85
6 Life is/was very good	0	0.00	0	0.00	0	0.00
7 Life is/was great	10	55.56	0	0.00	1	3.85

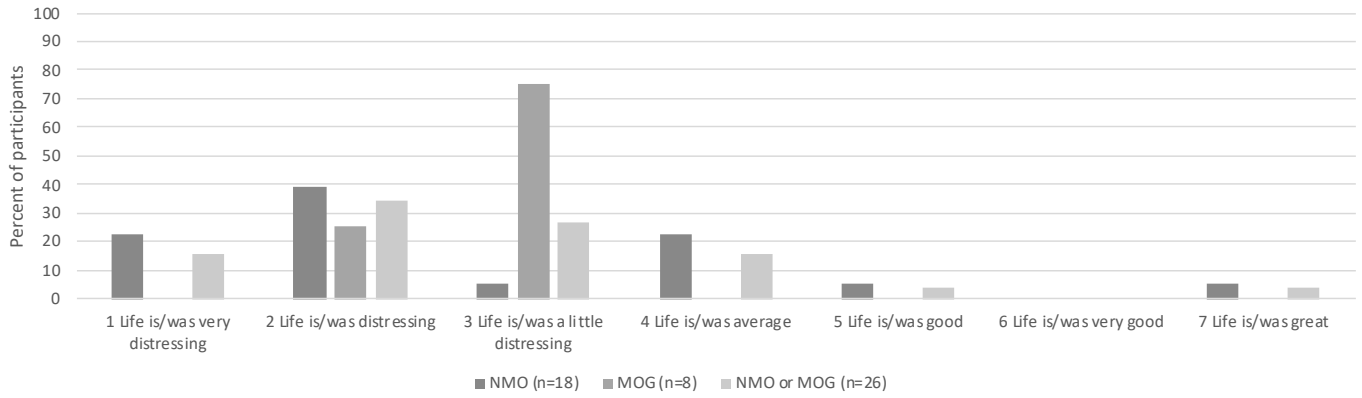

Figure 8.9: Overall impact of NMOSD on quality of life

Experience of anxiety related to disease progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their condition. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Summary statistics for the entire cohort are displayed in Table 8.8. Overall the NMOSD cohort had a mean total score of 41.33 (SD = 8.90), which corresponds to high levels of anxiety (Table 8.18)

Comparisons of Fear of progression have been made based on **participant type** (Tables 8.19 to 8.20, Figure 8.10), **relapse** (Table 8.21, Figure 8.11), **physical function** (Table 8.22, Figure 8.12), **education,** (Table 8.23, Figure 8.13), **socioeconomic advantage** (Tables 8.24, Figure 8.15), **age** (Table 8.25, Figure 8.15), **gender** (Table 8.26), and **location** (Table 8.27). No analysis by the **fear of progression** subgroups have been conducted to avoid bias.

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their condition. Overall, the average fear of progression score for NMOSD participants in this study indicated high levels of anxiety.

Table 8.18: Fear of progression summary statistics

Fear of progression	Mean	SD	Median	IQR	Possible range	Quintile
NMOSD* (n=18)	41.33	8.90	41.5	12.5	12 to 60	4

*Normal distribution use mean and SD as measure of central tendency

Comparisons of Fear of progression total score scales by participant type

Participant type were grouped according to diagnosis of NMOSD, MOG, and family and carers; the *NMOSD* group includes participants who had a NMOSD diagnosis, (n=18, 50.00%), participants who had a MOG diagnosis were included in the *MOG* group (n=8, 22.22%), participants in the *NMOSD or MOG* groups were included in the *NMOSD and MOG* subgroup (n=26, 72.22), and family members or carers of people with NMOSD or MOG were included in the *Family and carers* subgroup (n=10, 27.78%).

Boxplots of each Fear of progression total score scale by **participant type** are displayed in Figure 8.10, summary statistics are displayed in Tables 8.19 and 8.20.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 8.19). A Tukey HSD test was used post hoc to identify the source of any differences identified in the one-way ANOVA test (Table 8.20).

A one way ANOVA test indicated a statistically significant difference in the **Fear of progression total score** scale between groups, F(3, 58) = 4.83 ,p 0.0045 (Table 8.10).

Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants in the *Family and carer* subgroup (Mean = 28.90, SD = 11.66) was significantly lower (less anxiety) compared to participants in the *NMOSD* (Mean = 41.33, SD = 8.90, p=0.0083), *MOG* (Mean = 41.50, SD = 9.68, p=0.0343), and *NMOSD or MOG* (Mean = 41.38, SD = 8.95, p=0.0044) subgroups.

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their condition, with a higher score denoting increased anxiety. On average, participants in the *Family and carer* subgroup scored lower than participants in the *NMOSD*, *MOG,* and *NMOSD or MOG* subgroups. This indicates that participants in the *Family and carer* subgroup were a little anxious, and those in the *NMOSD*, *MOG,* and *NMOSD or MOG* subgroups, were very anxious about their condition.

Table 8.19: Fear of progression total score by participant type ANOVA test

Fear of progression	Group	Number (n=36)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	NMOSD	18	50.00	41.33	8.90	Between groups	1307.00	3	435.80	4.83	0.0045*
	MOG	8	22.22	41.50	9.68	Within groups	5231.00	58	90.20		
	NMOSD and MOG	26	72.22	41.38	8.95	Total	6538.00	61			
	Family and carers	10	27.78	28.90	11.66						

*significant at p<0.05

Table 8.20: Fear of progression total score by participant type post hoc Tukey HSD test

Fear of progression	Group	Difference	Lower	Upper	P adjusted
Total score	MOG - NMOSD	0.17	-10.51	10.84	1.0000
	NMOSD and MOG - NMOSD	0.05	-7.65	7.75	1.0000
	Family and carers - NMOSD	-12.43	-22.34	-2.53	0.0083*
	NMOSD - MOG	-0.12	-10.27	10.04	1.0000
	Family and carers - MOG	-12.60	-24.52	-0.68	0.0343*
	Family and carers - NMOSD and MOG	-12.48	-21.83	-3.14	0.0044*

*significant at p<0.05

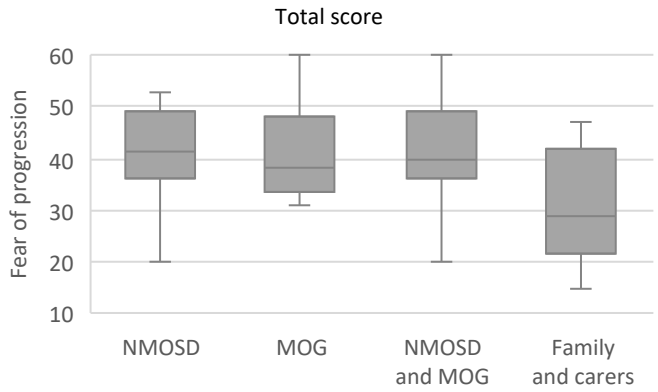

Figure 8.10: Boxplot of Fear of progression total score by participant type

Comparisons of Fear of progression total score scales by relapse

Comparisons were made by NMOSD relapses, those less than two relapses were included in the *fewer relapses* subgroup (n=9, 50.00%), and those that had three or more relapses, in the *more relapses* subgroup (n=9, 50.00%). Only participants with NMOSD were included in this comparison.

Boxplots of each Fear of progression total score scale by **relapse** are displayed in Figure 8.11, summary statistics are displayed in Table 8.21. Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.21).

No significant differences were observed between participants in the subgroup F*ewer relapses* compared to those in the *More relapses* subgroup for the Fear of progression total score.

Table 8.21: Fear of progression total score by relapse summary statistics and two sample t-test

Fear of progression	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Total score	*Fewer relapses*	9	50.00	40.00	7.47	-0.62	16	0.5416
	More relapses	9	50.00	42.67	10.43			

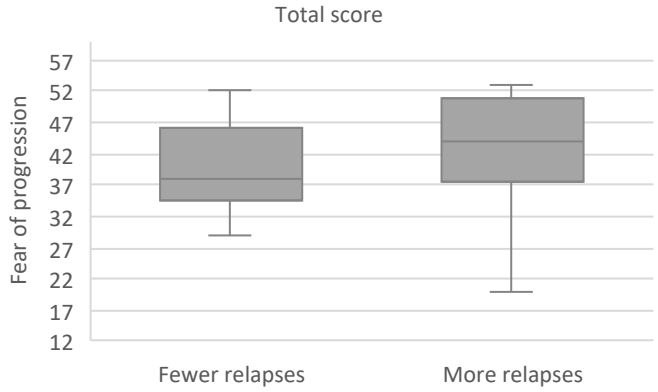

Figure 8.11: Boxplot of Fear of progression total score by relapse

Comparisons of Fear of progression total score scales by physical function

The SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. Comparisons were made by **physical function**, participants that scored in the lowest three quintiles of the SF36 Physical functioning scale were included in the *Moderate to very poor physical function* subgroup (n=9, 50.00%), and participants that scored in the highest two quintiles were included in the *Good to very good physical function* subgroup (n=9, 50.00%). Only participants with NMOSD were included in this comparison.

Boxplots of each Fear of progression total score scale by **physical function** are displayed in Figure 8.12, summary statistics are displayed in Table 8.22. Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.22).

No significant differences were observed between participants in the *Moderate to very poor physical function* subgroup compared to those in the *Good to very good physical function* subgroup for the Fear of progression total score.

Table 8.22: Fear of progression total score by physical function summary statistics and two sample t-test

Fear of progression	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Total score	*Moderate to very poor physical function*	9	50.00	43.67	7.94	1.12	16	0.2792
	Good to very good physical function	9	50.00	39.00	9.66			

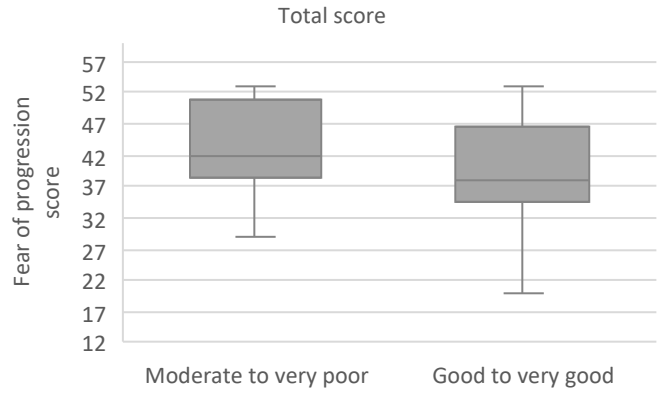

Figure 8.12: Boxplot of Fear of progression total score by physical function

Comparisons of Fear of progression total score scales by education

Comparisons were made by **education** status, between those with trade or high school qualifications, *Trade or high school* (n=10, 55.56%), and those with a university qualification, *University* (n= 8, 44.44%). Only participants with NMOSD were included in this comparison.

Boxplots of each Fear of progression total score scale by **education** are displayed in Figure 8.13, summary statistics are displayed in Table 8.23. Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.23).

A two sample t-test indicated that the mean score for the **Fear of progression total score** [t(16) = 0.0122 p=0.0122] was significantly higher (less anxiety) for participants in the *Trade or high school* subgroup (Mean = 45.80, SD = 5.67) compared to participants in the *University* subgroup (Mean = 35.75, SD = 9.33).

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their condition, with a higher score denoting increased anxiety. On average, participants in the *University* subgroup scored lower than participants in the *Trade or high school* subgroups. This indicates that participants in the *University* subgroup were a little anxious, and those in the *Trade or high school* subgroup, were moderately anxious about their condition.

Table 8.23: Fear of progression total score by education summary statistics and two sample t-test

Fear of progression	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Total score	*Trade or high school*	10	55.56	45.80	5.67	2.83	16	0.0122*
	University	8	44.44	35.75	9.33			

*significant at p<0.05

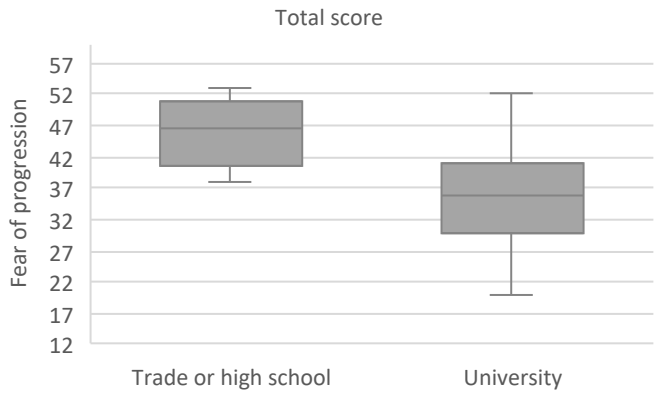

Figure 8.13: Boxplot of Fear of progression total score by education

Comparisons of Fear of progression total score scales by socioeconomic status

Comparisons were made by socioeconomic advantage, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, *Mid to low status* (n=6, 33.33%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n=12, 66.67%) . Only participants with NMOSD were included in this comparison.

Boxplot of the Fear of progression total score scale by **socioeconomic advantage** are displayed in Figure 8.14, summary statistics are displayed in Table 8.24. Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.24).

No significant differences were observed between participants in the *Mid to low status* subgroup compared to those in the *Higher status* subgroup for the **Fear of progression total score**.

Table 8.24: Fear of progression total score by socioeconomic status summary statistics and two sample t-test

Fear of progression	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Total score	*Mid to low status*	6	33.33	44.50	5.47	1.07	16	0.2998
	Higher status	12	66.67	39.75	10.04			

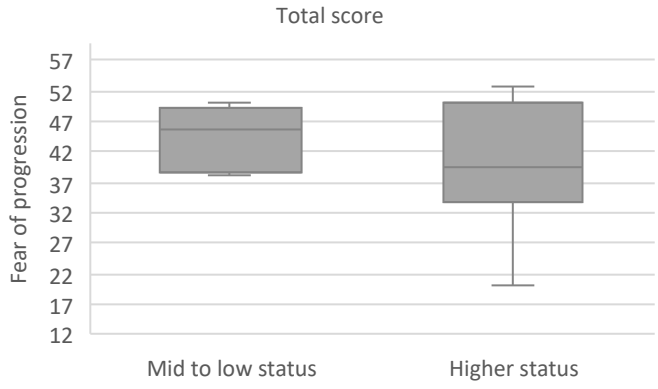

Figure 8.14: Boxplot of Fear of progression total score by socioeconomic status

Comparisons of Fear of progression total score scales by age

Participants were grouped according to **age,** with comparisons made between participants *Aged 18 to 44* (n=7, 38.89%), , and *Aged 45 or older* (n=11, 61.11%). Only participants with NMOSD were included in this comparison.

Boxplots of each Fear of progression total score scale by **age** are displayed in Figure 8.15, summary statistics are displayed in Table 8.25. Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.25).

No significant differences were observed between participants in the *Aged 18 to 44* subgroup compared to those in the *Aged 45 or older* for the fear of progression total score.

Table 8.25: Fear of progression total score by age summary statistics and two sample t-test

Fear of progression	Group	Number (n=18)	Percent	Mean	SD	t	dF	p-value
Total score	*Aged 18 to 44*	7	38.89	40.57	11.75	-0.28	16	0.7818
	Aged 45 or older	11	61.11	41.82	7.17			

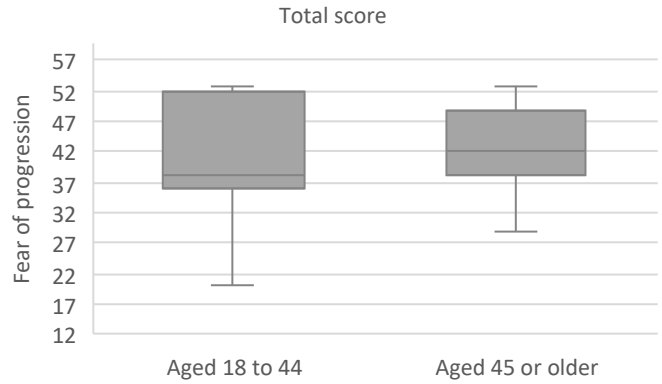

Figure 8.15: Boxplot of Fear of progression total score by age

Comparisons of Fear of progression total score scales by gender

There were 16 *Females* (n=16, 88.89%) with NMOSD, however, there were too few *Males* (n=2, 11.11%) for comparisons to be made. Data by gender is displayed for NMOSD participants in Table 8.26, but no analysis conducted.

Table 8.26: Fear of progression total score by gender summary statistics

Fear of progression	Group	Number (n=18)	Percent	Mean	SD	Median	IQR
Total score	*Female*	16	88.89	40.06	8.61	40.00	9.25
	Male	2	11.11	51.50	2.12	51.50	1.50

Comparisons of Fear of progression total score scales by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. There were 15 participants with NMOSD (83.33%) that lived in *Metropolitan* areas, however, too few participants with NMOSD lived in *Regional or remote* areas (16.67%) for comparisons to be made. Data by location is displayed for NMOSD participants is displayed in Table 8.27, but no analysis conducted.

Table 8.27: Fear of progression total score by location summary statistics

Fear of progression	Group	Number (n=18)	Percent	Mean	SD	Median	IQR
Total score	*Female*	16	88.89	40.06	8.61	40.00	9.25
	Male	2	11.11	51.50	2.12	51.50	1.50

Fear of progression: individual questions by NMOSD

The responses to individual questions of the Fear of Progression questionnaire for participants with NMOSD are displayed in Table 8.19, and Figure 8.15.

There were 50% or more participants that were often or very often worried about; disease progression (n=11, 61.11%), reaching professional or personal goals (n=12, 66.67%), relatives being diagnosed with disease (n=9, 50.00%), being able to pursue hobbies (n=15, 83.33%), treatment will damage body (n=11, 61.11%), worried about family if anything happens to them (n=11, 61.11%), and not being able to work (n=9, 50.00%).

Table 8.28: Fear of progression questionnaire: individual questions by NMOSD

Fear of progression	Never to sometimes		Often and Very often	
	n=18	%	n=18	%
I become anxious if I think my disease may progress	7	38.89	11	61.11
I am nervous prior to doctors appointments or periodic examinations	10	55.56	8	44.44
I am afraid of pain	12	66.67	6	33.33
I have concerns about reaching my professional and/or personal goals because of my illness	6	33.33	12	66.67
When I am anxious, I have physical symptoms such as a rapid heartbeat, stomach ache or agitation	15	83.33	3	16.67
The possibility of my relatives being diagnosed with this disease disturbs me	9	50.00	9	50.00
It disturbs me that I may have to rely on strangers for activities of daily living	10	55.56	8	44.44
I am worried that at some point in time I will no longer be able to pursue my hobbies because of my illness	3	16.67	15	83.33
I am afraid of severe medical treatments during the course of my illness	11	61.11	7	38.89
I worry that my treatment could damage my body	7	38.89	11	61.11
I worry about what will become of my family if something should happen to me	7	38.89	11	61.11
The thought that I might not be able to work due to my illness disturbs me	9	50.00	9	50.00
If I am on a treatment and it is working well for me (limited side effects, no progression of disease), I worry what will happen if I stop treatment	10	55.56	8	44.44
I become anxious if I am not experiencing any side effects of treatment as it makes me think that the treatment isn't working	18	100.00	0	0.00

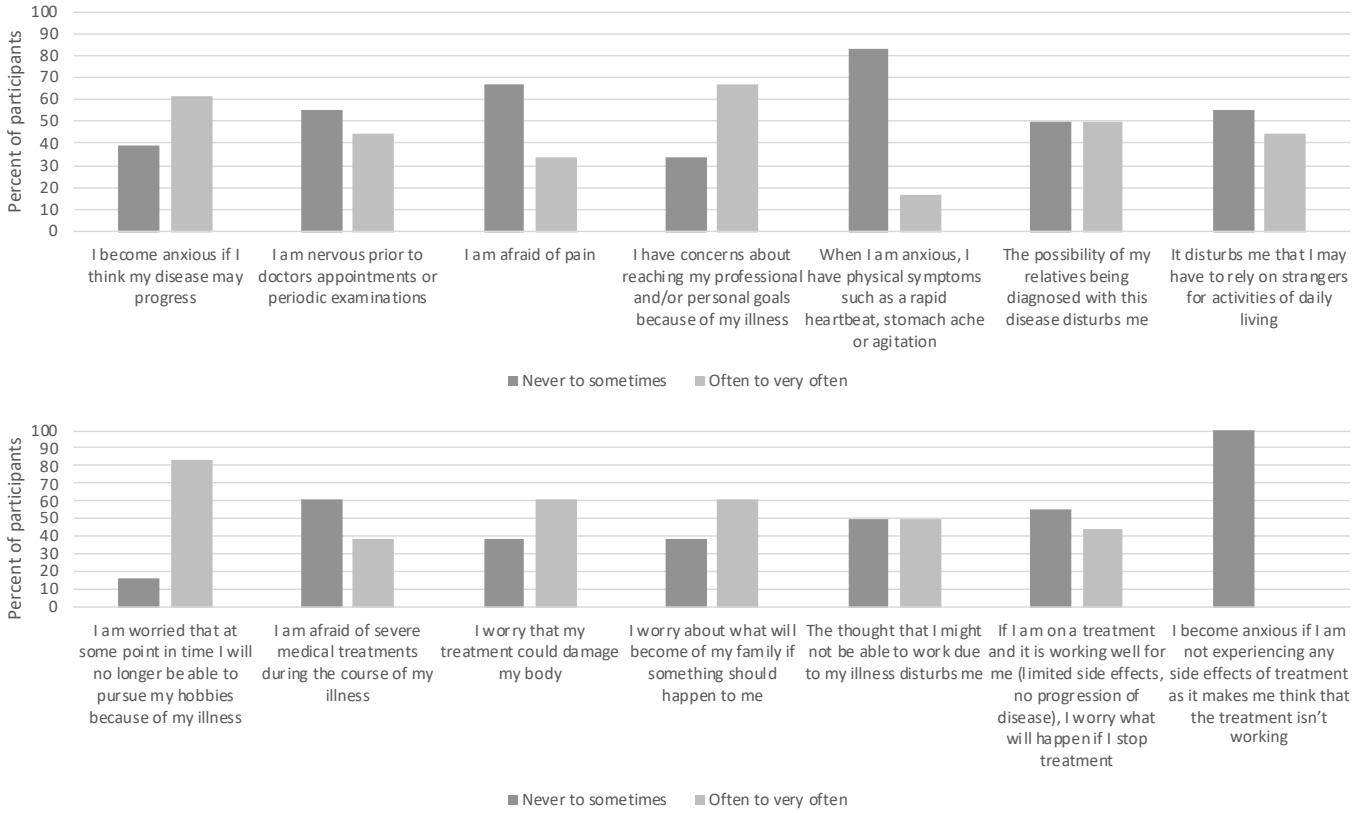

Figure 8.16: Fear of progression questionnaire: individual questions by NMOSD

Fear of progression question by question

The average score for each of the 12 fear of progression questions are presented in Table 8.29 and Figure 8.17. For each question, participants respond to each question using the following scale:

- Never
- Seldom
- Sometimes
- Often
- Very often

A numerical score is given for each response, where "Never" is equal to 1, and "Very often" is equal to 5. A higher score denotes more anxiety.

Participants in this study were most anxious about:

- Being unable to pursue hobbies
- Their family if something happens to them
- Reaching professional and personal goals
- Disease progression

Table 8.29: Fear of progression question by question overview

Question	Average score
become anxious if I think my disease may progress	3.78
I am nervous prior to doctors appointments or periodic examinations	3.56
I am afraid of pain	3.11
I have concerns about reaching my professional and/or personal goals because of my illness:	3.83
When I am anxious, I have physical symptoms such as a rapid heartbeat, stomach ache or agitation	2.67
The possibility of my relatives being diagnosed with this disease disturbs me	3.22
It disturbs me that I may have to rely on strangers for activities of daily living	3.33
I am worried that at some point in time I will no longer be able to pursue my hobbies because of my illness	4.17
I am afraid of severe medical treatments during the course of my illness	3.06
I worry that my treatment could damage my body	3.39
I worry about what will become of my family if something should happen to me	4.00
The thought that I might not be able to work due to my illness disturbs me	3.22

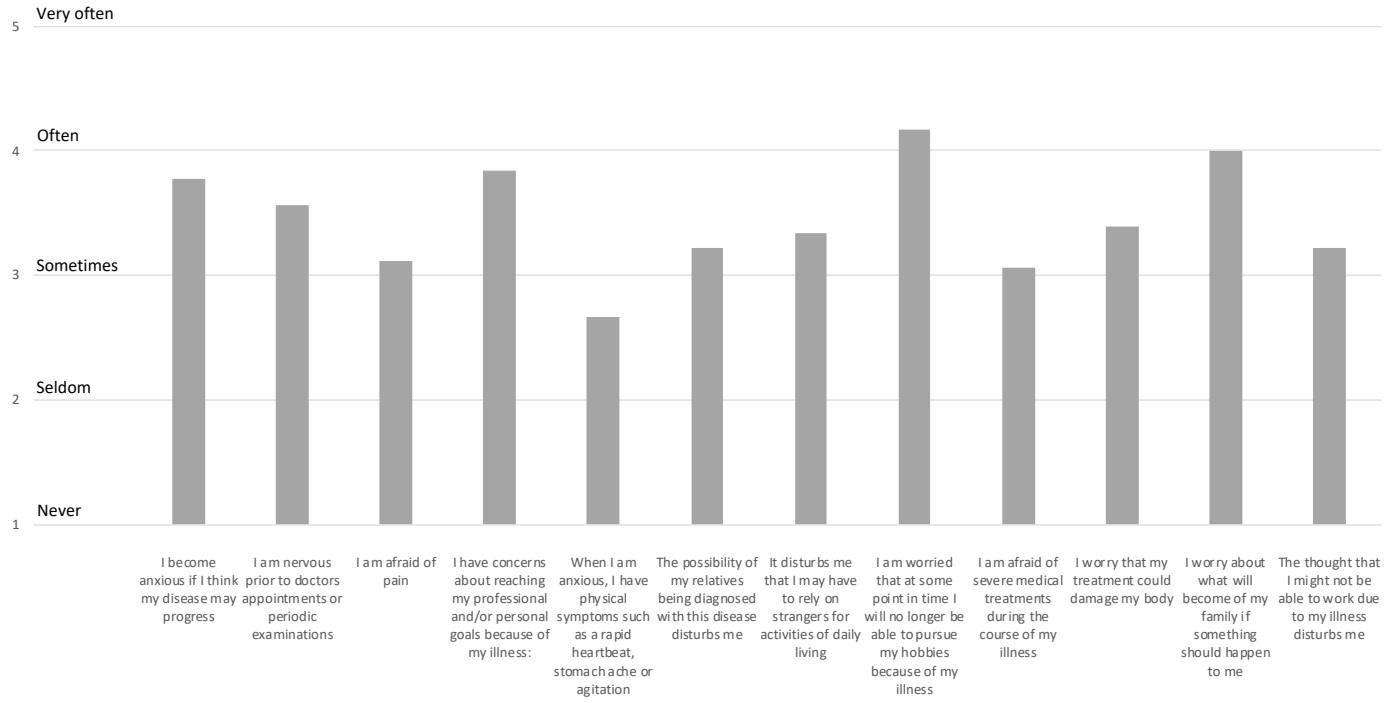

Figure 8.17: Fear of progression question by question overview

Section 9

Expectations and messages to decision-makers

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common theme was that future treatments will have fewer or less intense side effects (n=6, 33.33%), and this was followed by the expectation that there will be more treatments available/options to treat their condition (e.g. treatments from overseas, those used to treat other conditions) (n=5, 27.78%).

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common theme was the expectation that future information will be more specific to their condition/disease (n=5, 27.78%).

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common theme was the expectation that future communication will be more transparent and information more forthcoming (n=7, 38.89%).

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online) (n=5, 27.78%).

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was low cost/free medical care (n=6, 33.33%). This was followed by being grateful for hospitals (n=6, 33.33%).

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported by participants with NMOSD were: weakness or paralysis of arms and legs, loss of clear vision, and loss of bowel or bladder control.

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care,. The most important aspects to participants with NMOSD were “How safe the medication is and weighing up the risks and benefits”, and “The severity of the side effects”. The least important was “My ability to follow and stick to a treatment regime”.

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The two most important values for participants with NMOSD were: quality of life for patients; and access for all patients to all treatments and services; the least important was economic value to government.

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure. The majority of participants with NMOSD (n=11, 64.11%) would use a treatment for more than 10 years for a good quality of life even if it didn't offer a cure. There were two participants (11.11%) that would take medication for five to 10 years, four participants (22.22%) that would take it for one to four years.

Most effective form of medicine

Participants were asked in the online questionnaire, In what form did they think medicine was most effective in. Participants with NMOSD most commonly responded that they were not sure (n=7, 38.89%), followed by IV form (n=6, 33.33%), and four participants (n=4, 22.22%) thought IV and pill forms were equally effective.

Messages to decision-makers

Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common message was to invest in new treatments and make them more accessible (n=7, 38.89%).

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common theme was that future treatments will have fewer or less intense side effects (n=6, 33.33%), and this was followed by the expectation that there will be more treatments available/options to treat their condition (e.g. treatments from overseas, those used to treat other conditions) (n=5, 27.78%).

Participant describes the expectation that future treatments will have fewer or less intense side effects

Well, it's probably a dream, but I'd like to see- the treatments at the moment are all like steroids with reduced inflammation and the immunosuppression stops further relapses in the future, what would be super cool is if something could be developed that actually remodel and fixes the nerves that can fix the damage that's already done because at the moment, that's the dream, we can't do that. Other than that, I mean, the steroids treatment is the first line and it's got such horrendous side effects. It's the worst. I'll avoid steroids as much as I can. I think they're awful.. Participant NMO_010

Well, less side effects would be fantastic. Participant NMO_016
I'm not sure if I am able to answer that because we have literally only used one or two treatments and I'm not sure whether I'm qualified, but just in overall, I think just the side effects, managing the side effects that would be perhaps the one that I would mention. Participant NMOCA_003

Participant describes the expectation that there will be more treatments available/options to treat their condition (e.g. treatments from overseas, those used to treat other conditions)

My neurologist there are new treatments for NMO in the US, but PBS doesn't have them or something. We just can't get it here, otherwise it would cost hundreds of thousands of dollars for an infusion. I guess more access to international drugs that are used and are effective and safe. Participant NMO_002

Like the doctors in LOCATION OVERSEAS-- To give you an example, doctors in LOCATION OVERSEAS, I'm constantly in contact with them. They told me, "Oh, maybe try tocilizumab," because I was relapsing in all the previous treatments. It's just not available. I had to write my neurologist a letter, she had to write to pharmaceutical companies, to medical boards, to everywhere, for it to get approved. Participant NMO_005

An injection would be great, or transfusion is fine, and a lot more affordable on the PBS would be amazing and more options because I feel like I don't have any options. Participant NMO_003

Participant describes expecting future treatments to be more affordable

The cost in regards to taking part in things that-- The NDIS doesn't cover pool access and all those kinds of things, which is hugely beneficial for me to be able to do. Participant NMO_006

It's just definitely the cost is a huge part of it. Participant NMO_014

Support with cost of ongoing treatment, better access to rehab facilities, and more priority around rehab. Participant NMOCA_002

Table 9.1: Expectations of future treatment

Expectations of future treatment	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes the expectation that future treatments will have fewer or less intense side effects	6	33.33	4	44.44	2	22.22	3	37.50	3	30.00	2	22.22	4	44.44
Participant describes the expectation that there will be more treatments available/options to treat their condition (e.g. treatments from overseas, those used to treat other conditions)	5	27.78	1	11.11	4	44.44	3	37.50	2	20.00	2	22.22	3	33.33
Participant describes expecting future treatments to be more affordable	3	16.67	1	11.11	2	22.22	1	12.50	2	20.00	1	11.11	2	22.22

Expectations of future treatment	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes the expectation that future treatments will have fewer or less intense side effects	6	33.33	3	30.00	3	37.50	3	50.00	3	25.00	3	42.86	3	27.27
Participant describes the expectation that there will be more treatments available/options to treat their condition (e.g. treatments from overseas, those used to treat other conditions)	5	27.78	3	30.00	2	25.00	2	33.33	3	25.00	3	42.86	2	18.18
Participant describes expecting future treatments to be more affordable	3	16.67	3	30.00	0	0.00	1	16.67	2	16.67	2	14.29	1	9.09

Expectations of future 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 the expectation that future treatments will have fewer or less intense side effects	6	33.33	5	62.50	11	42.31	4	40.00	6	37.50	0	0.00	0	0.00	6	40.00
Participant describes the expectation that there will be more treatments available/options to treat their condition (e.g. treatments from overseas, those used to treat other conditions)	5	27.78	0	0.00	5	19.23	1	10.00	4	25.00	1	50.00	2	66.67	3	20.00
Participant describes expecting future treatments to be more affordable	3	16.67	1	12.50	4	15.38	1	10.00	3	18.75	0	0.00	0	0.00	3	20.00

Table 9.2: Expectations of future treatment (Subgroup variations)

Expectations of future treatment	More frequent	Less frequent
Participant describes the expectation that future treatments will have fewer or less intense side effects	Fewer relapses Good to very good physical function Mid to low socioeconomic status	More relapses Moderate to very poor physical function
Participant describes the expectation that there will be more treatments available/options to treat their condition (e.g. treatments from overseas, those used to treat other conditions)	More relapses Aged 18 to 44	Fewer relapses

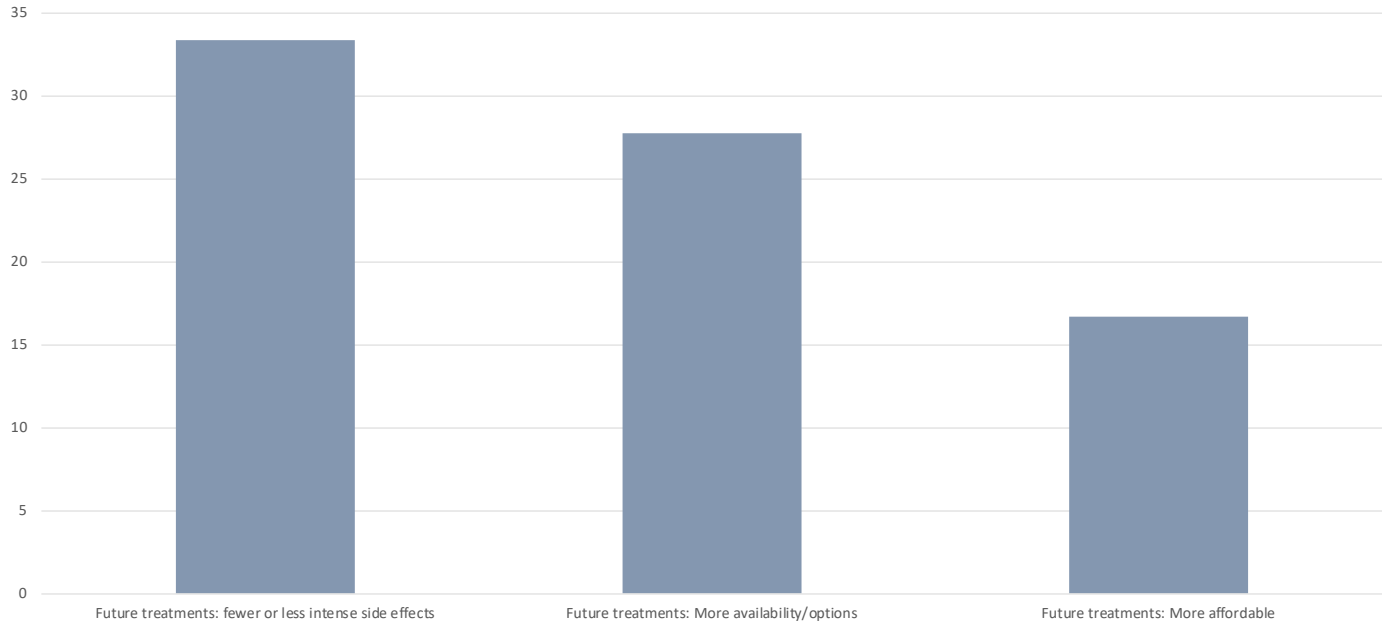

Figure 9.1: Expectations of future treatment

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common theme was the expectation that future information will be more specific to their condition/disease (n=5, 27.78%).

Participant describes the expectation that future information will be more specific to their condition/disease

I just think maybe more information on it. I just feel like it's under the branch of MS, and that's kind of all there really is. They used to think it was a type of MS but now it's not, and it's worse. I just wish there was more accurate information out there that wasn't under the umbrella of MS because I feel like MS is gets all the funding. MS gets all the like the Readathon, the walkathons. They get all the funding, and it's kind of like what about NMO?..., I just feel like NMO gets forgotten about. Participant NMO_003

I think the information is getting better. I think it's one of those things where it's a rare disease and it affects so few people, but also there just isn't a lot of information about. Even the medications we use, they're not really NMO medications. They're medications for other diseases that we know kind of work. I don't know, I would like-it's probably a dream too, but I would like the neurologists and the research clinics that I've been to be a little bit more accommodating, where you can ask questions. Participant NMO_010

Just that it is presented. The only thing that they could refer me to was a place called Sparks and everything that was related to NMO was through MS. Yet MS and NMO are treated so differently. I would like to see it have a home of its own. Do you know what I mean. Participant NMO_011

Participant describes the expectation that future information will provide more details about where to find available services

What services that they can have, because like some people, it might be in their spine, or hip first, so it'd be more the transverse. It might be physiotherapy for being able to walk again. Just certain specialists maybe be a helpline like in Australia, or whatever, anyway. It might be like the NDIS or whatever, because of some disabilities. Participant NMO_012

I think there just needs to be information about support thing, like where people can get support but that's about it. Participant NMOCA_005

I think when you're initially diagnosed with the condition, it would be really, really beneficial to have some leaflet or information on the condition itself, the treatment options that are used to treat the condition, and maybe some literature on where to find help and support. Participant NMOCA_007

Table 9.3: Expectations of future information

Expectations of future information	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 the expectation that future information will be more specific to their condition/disease	5	27.78	2	22.22	3	33.33	3	37.50	2	20.00	2	22.22	3	33.33
Participant describes the expectation that future information will provide more details about where to find available services	2	11.11	0	0.00	2	22.22	0	0.00	2	20.00	1	11.11	1	11.11

Expectations of future information	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 the expectation that future information will be more specific to their condition/disease	5	27.78	3	30.00	2	25.00	1	16.67	4	33.33	3	42.86	2	18.18
Participant describes the expectation that future information will provide more details about where to find available services	2	11.11	2	20.00	0	0.00	1	16.67	1	8.33	0	28.57	2	18.18

Expectations of future information	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 the expectation that future information will be more specific to their condition/disease	5	27.78	2	25.00	7	26.92	2	20.00	5	31.25	0	0.00	1	33.33	4	26.67
Participant describes the expectation that future information will provide more details about where to find available services	2	11.11	1	12.50	3	11.54	3	30.00	1	6.25	1	50.00	1	33.33	1	6.67

Table 9.4: Expectations of future information (Subgroup variations)

Expectations of future information	More frequent	Less frequent
Participant describes the expectation that future information will be more specific to their condition/disease	Aged 18 to 44	Mid to low socioeconomic status

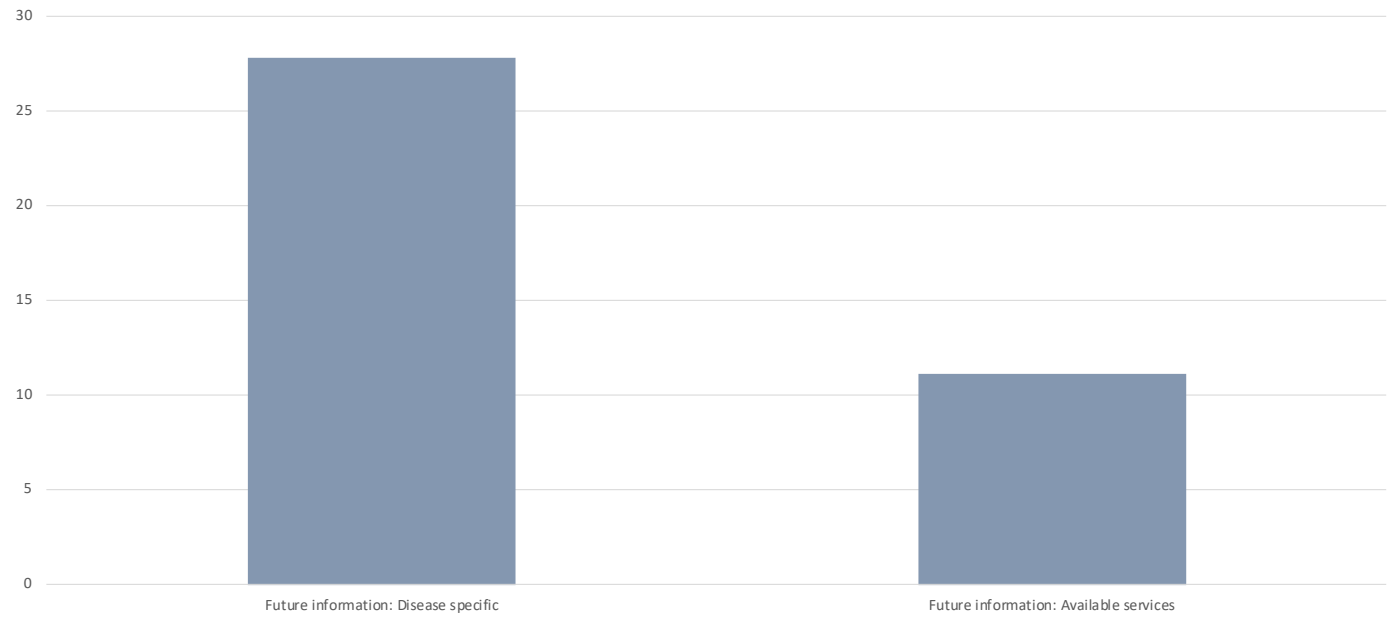

Figure 9.2: Expectations of future information

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common theme was the expectation that future communication will be more transparent and information more forthcoming (n=7, 38.89%).

Participant describes the expectation that future communication will be more transparent and information more forthcoming

I think yes. I think if we could communicate, it's sometimes really difficult to get any answers, especially early on, when things are changing so rapidly. I found the process of contacting the MS nurse and then waiting for a reply until she contacted the neurologist, it could take several days, and sometimes you do need to find out if there was an answer. You feel like you've been forgotten. I think prompt delivery of information when a patient's looking for it would be really good. Participant NMO_004

Yes, discuss in the room not out of the room. That's the first thing. Not when you're walking down the hallway with me. Explain, don't just do tests and then say, "Yes, it's all good," and then not tell you what's happened in there. I've got all these lesions that I didn't even know about. I had the disease for a couple of years and didn't even know about it. I had to find out from another doctor, things like that. Tell me what I may expect. Just be a little bit more informative. Participant NMO_011

Some dialogue would be very nice, even if they just say like, actually tells you, "This is how we've come about the diagnosis and this is what it means. These are the testing that we've done." Just the information about your health that should be available to you. Participant NMO_014

Participant describes the expectation that future communication will allow people more time to meet with their clinician to talk about all that they need to talk about

I wish they had a bit more time rather than rushing to see the next patient particularly in the first couple of weeks really give us the time that we need, I feel like even 45 minutes to an hour, whatever it might be because if it's new just go through everything even if it needs to be repeated a couple of times and then really just make you understand what it is about that we are dealing with now and what the treatments are. Participant NMOCA_003

Like I say, just what I said is probably a bit more contact. We've got a lady, MS nurse, that we've got those details of. I think they should have more of those ladies and they could ring the patients up and see how they're going every three months, would be really awesome. I think for the patient, I think you need that. I think NAME PERSON CARED

FOR feels like she just has the treatment and then off she goes. "See you next year." I just think-- Like I say, I know time's important to them. That's the only thing really. Participant NMOCA_005

What I found with mine because, obviously, the neurologist is very busy, so he has an MS nurse who books you in or if you have any questions or concerns, you can message them or contact them. I've found that over three years, and I know they're busy too, it might be a week, sometimes they're off a week or they're on holiday, you never get your messages returned. Participant NMO_013

Participant describes the expectation that future communication will include listening to the patient, as they know their body best

Certainly having that empathy maybe that they just listen, listen to what she's saying because she's giving you all the clues that you need to see that she needs some assistance. It can be very frustrating. Participant NMO_016

I think listening to what a patient wants and needs, and I have to sort of try and work in with what's in that person's life. Like you can't just take time off because they want to start you on this new drug and just little things like that to me-- I'm a pretty stubborn personality and I can articulate how I feel because I've got a medical background. I think that's made a big difference where when I went to the NMO patient day, people don't speak to their neurologist. They don't articulate exactly what they want. They just go along with doctor knows best, but I don't think that's always the case. I think the patient actually has a voice and they should be given that opportunity to actually voice it, what it is, whatever it may be they want. Participant NMO_017

Participant describes the expectation that future communication will be more empathetic

I think if they just could communicate instead of they're looking at all the numbers of blood tests and all that stuff. They do a fantastic job. They need to have more of a sympathetic thing. It's like, "Okay. Well, what are they going to be feeling after this diagnosis?" Just to have a bit of a heart. Instead of just thinking, "Okay. This is another person. This is number 50. This is their diagnosis, let them go. This is the treatment." It's just seems like they're just concerned about just the treatment and not the person. Participant NMO_012

Probably a little bit more empathy or compassion. Participant NMOCA_007

Yes. I think mostly like the allied health that I've seen has been really awesome. The physios and OTs and even a dietitian has been- that part's been really good, but the specialists I found just quite difficult to ask questions or to have them communicate it at the right level. I feel like- I was sent to this research centre, which is great, it's where I wanted to be, but every time I went there, I felt like the little subject that's come in for their tests and they're sent away, but not like a person. Participant NMO_010

Participant describes the expectation that in the future health professionals have a better understanding of the condition they a treating

Yes. I find sometimes say you go and it maybe you see something that you're trying to explain to them and you get hit on the head. I've gone through it. I know if I go in "Oh, you've got arthritis." Oh, my neurologist some 15 years ago told me I was lazy. "Go and do an exercise," and things like that. What I'm trying to say is these things are happening, but they don't know themselves sometimes. I was sent from one doctor who was very good in LOCATION METROPOLTIAN. He couldn't find out what was wrong with me. There was another doctor, I don't know what they call him. If there's something that's wrong with you and the doctor can't find it, he will send you to NAME DOCTOR. He was the one that done all the tests. Yes, so what I'm trying to say is so he was thorough, but then he had diagnosed me with MS because he'd never heard of NMO anyway. Participant NMO_013

I think they should be more informed about diseases such as NMO and MOG, because every single time I've been to the emergency, they just don't understand. Participant NMO_005

I guess more awareness. I think the issue is a lot of medical professionals are a little bit out of their depth when it comes to the disease, so a little bit more awareness or knowledge about it. Participant NMOCA_007

Participant has no recommendations/experienced good communication

No, that part is all good. Like I said, the neurologist, he's very good. Participant NMO_007

No, I find they've been fantastic both the neurologist and the physio, so the communication's been fine. Participant NMO_009

Not really. I think no. I think I've got a pretty good team. I think I'm lucky in that sense. Participant NMOCA_005

Table 9.5: Expectations of future healthcare professional communication

Expectations of future communication	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes the expectation that future communication will be more transparent and information more forthcoming	7	38.89	3	33.33	4	44.44	5	62.50	2	20.00	4	44.44	3	33.33
Participant describes the expectation that future communication will allow people more time to meet with their clinician to talk about all that they need to talk about	3	16.67	1	11.11	2	22.22	0	0.00	3	30.00	1	11.11	2	22.22
Participant describes the expectation that future communication will include listening to the patient, as they know their body best	3	16.67	1	11.11	2	22.22	2	25.00	1	10.00	1	11.11	2	22.22
Participant describes the expectation that future communication will be more empathetic	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	0	0.00	2	22.22
Participant describes the expectation that in the future health professionals have a better understanding of the condition they a treating	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	1	11.11	1	11.11
Participant has no recommendations/experienced good communication	2	11.11	1	11.11	1	11.11	0	0.00	2	20.00	2	22.22	0	0.00

Expectations of future communication	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes the expectation that future communication will be more transparent and information more forthcoming	7	38.89	4	40.00	3	37.50	2	33.33	5	41.67	3	42.86	4	36.36
Participant describes the expectation that future communication will allow people more time to meet with their clinician to talk about all that they need to talk about	3	16.67	2	20.00	1	12.50	2	33.33	1	8.33	2	42.86	1	9.09
Participant describes the expectation that future communication will include listening to the patient, as they know their body best	3	16.67	1	10.00	2	25.00	1	16.67	2	16.67	2	28.57	1	9.09
Participant describes the expectation that future communication will be more empathetic	2	11.11	1	10.00	1	12.50	1	16.67	1	8.33	1	14.29	1	9.09
Participant describes the expectation that in the future health professionals have a better understanding of the condition they a treating	2	11.11	1	10.00	1	12.50	0	0.00	2	16.67	1	14.29	1	9.09
Participant has no recommendations/experienced good communication	2	11.11	2	20.00	0	0.00	1	16.67	1	8.33	0	0.00	2	18.18

Expectations of future communication	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 the expectation that future communication will be more transparent and information more forthcoming	7	38.89	1	12.50	8	30.77	3	30.00	7	43.75	0	0.00	1	33.33	6	40.00
Participant describes the expectation that future communication will allow people more time to meet with their clinician to talk about all that they need to talk about	3	16.67	1	12.50	4	15.38	3	30.00	3	18.75	0	0.00	0	0.00	3	20.00
Participant describes the expectation that future communication will include listening to the patient, as they know their body best	3	16.67	1	12.50	4	15.38	1	10.00	3	18.75	0	0.00	0	0.00	3	20.00
Participant describes the expectation that future communication will be more empathetic	2	11.11	1	12.50	3	11.54	3	30.00	2	12.50	0	0.00	1	33.33	1	6.67
Participant describes the expectation that in the future health professionals have a better understanding of the condition they a treating	2	11.11	2	25.00	4	15.38	1	10.00	2	12.50	0	0.00	0	0.00	2	13.33
Participant has no recommendations/experienced good communication	2	11.11	3	37.50	5	19.23	0	0.00	0	0.00	2	100.00	1	33.33	1	6.67

Table 9.6: Expectations of future healthcare professional communication (Subgroup variations)

Expectations of future communication	More frequent	Less frequent
Participant describes the expectation that future communication will be more transparent and information more forthcoming	Low to moderate fear	High to very high fear

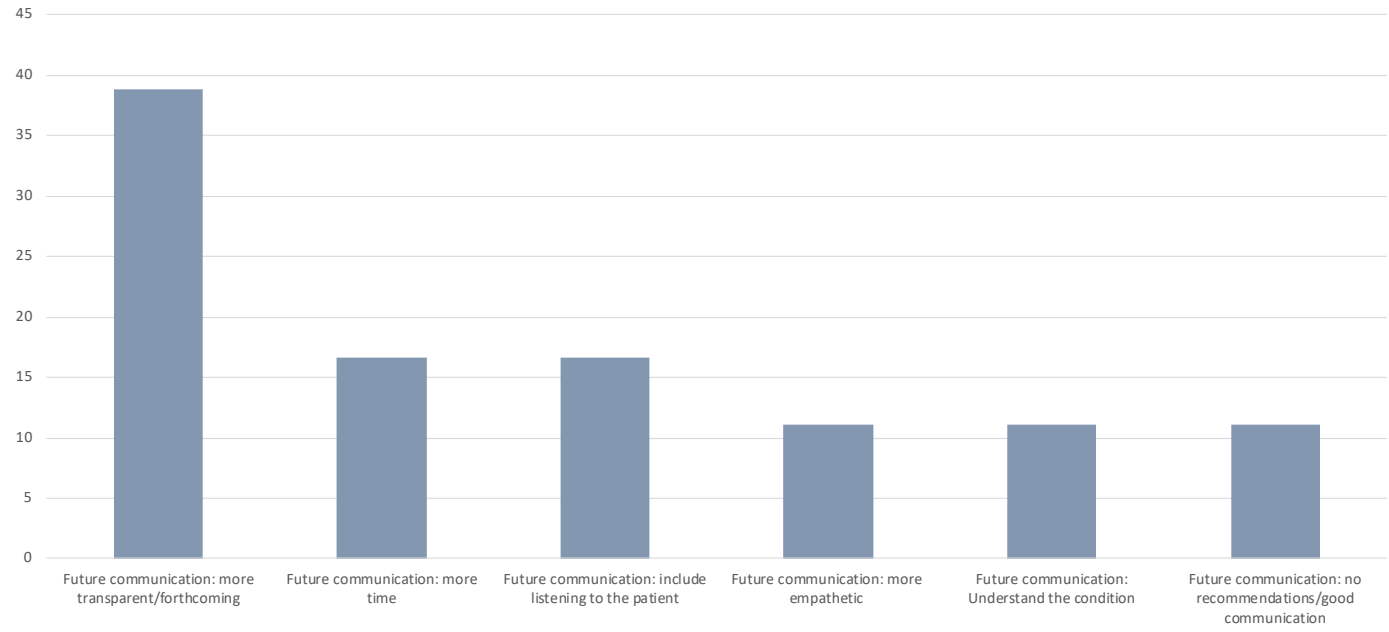

Figure 9.3: Expectations of future healthcare professional communication

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online) (n=5, 27.78%).

Participant describes the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)

It would be nice to have a specialist that does even just research or something that you can talk to or whatever. They can say yay or nay. Participant NMO_013

Like some sort of a club is one. When something is happening to be able to reach out and talk to someone and say, "Look, XYZ is going on, what should I do?" Do I take her to hospital, do I-- I don't know, go to the GP? Where do we go from here? Someone that actually knows about the condition because the symptoms that she displays are so different to anything else. She doesn't get a fever like normal people get a fever because of the damage in her spinal cord. Participant NMO_016

I think maybe having someone there that you could talk to maybe about it and obviously that person knowing the condition being able to give you answers. Participant NMOCA_006

Participant describes the expectation that future care and support will be more specific to their condition and have more specific information

I don't know if this relates, but I feel like it would be great if we would have an organisation here that would help with, for example, audiobooks, or those kinds of things, because I've seen in America, they have quite a few organisations, and I feel like we don't. Participant NMO_005

I guess like a booklet or a pamphlet like something about NMO in Australia where there are support groups or doctors or rehab facilities that that are there for the therapy with NMO. Participant NMO_002

Research into the disease and information. Get the word out there what it's about. Participant NMO_011

Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)

I think I've touched on that before. I think just continuing to have our own support groups with NMO People. Participant NMO_004

Some kind of support network or some kind, just so that if somebody's newly diagnosed, that may be like, we now on part of the NMOSD Australia page, and since now, I'd be happy to give my details through them. I know there's a mentoring type thing that a few of us are taking part in. If somebody gets an early diagnosis, telling them that there's this page, there's these people contact them, and they'll see if there's somebody who could just keep checking in with the people. Participant NMO_006

I guess maybe more support groups. Participant NMO_008

Participant describes the expectation that future care and support will include more access to support services (general) (e.g. social workers, transport services, NDIS etc.)

I think more support to the families, a contact for the family to actually contact with. They may need support caring for somebody. I'd like to see, either it'd be a social worker. I know that there's people trying to navigate around NDIS around what they're entitled to and that can be really difficult for people who aren't into the medical profession. Participant NMO_017

I suppose looking after NAME PERSON CARED FOR myself, no one has reached out and said, "This is what is available to you as the carer." Not so much NAME PERSON CARED FOR, because they've got a whole team looking after her, or just being aware of what's around there. Participant NMOCA_004

My greatest problem is really transportation, because I don't drive, I've had to depend on others. Participant NMO_007

Table 9.7: Expectations of future care and support

Expectations of future care and support	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very goo physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant describes the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	5	27.78	3	33.33	2	22.22	2	25.00	3	30.00	3	33.33	2	22.22
Participant describes the expectation that future care and support will be more specific to their condition and have more specific information	4	22.22	2	22.22	2	22.22	4	50.00	0	0.00	2	22.22	2	22.22
Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)	4	22.22	1	11.11	3	33.33	2	25.00	2	20.00	2	22.22	2	22.22
Participant describes the expectation that future care and support will include more access to support services (general) (e.g. social workers, transport services etc.)	2	11.11	1	11.11	1	11.11	1	12.50	1	10.00	1	11.11	1	11.11

Expectations of future care and support	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant describes the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	5	27.78	4	40.00	1	12.50	2	33.33	3	25.00	1	14.29	4	36.36
Participant describes the expectation that future care and support will be more specific to their condition and have more specific information	4	22.22	2	20.00	2	25.00	2	33.33	2	16.67	1	28.57	3	27.27
Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)	4	22.22	1	11.11	3	33.33	2	25.00	2	20.00	2	28.57	2	18.18
Participant describes the expectation that future care and support will include more access to support services (general) (e.g. social workers, transport services etc.)	2	11.11	1	10.00	1	12.50	0	0.00	2	16.67	0	0.00	2	18.18

Expectations of future care and support	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 the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	5	27.78	0	0.00	5	19.23	1	10.00	5	31.25	0	0.00	0	0.00	5	33.33
Participant describes the expectation that future care and support will be more specific to their condition and have more specific information	4	22.22	3	37.50	7	26.92	3	30.00	4	25.00	0	0.00	1	33.33	3	20.00
Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)	4	22.22	1	12.50	5	19.23	2	28.57	4	25.00	0	0.00	0	0.00	4	26.67
Participant describes the expectation that future care and support will include more access to support services (general) (e.g. social workers, transport services etc.)	2	11.11	1	12.50	3	11.54	3	30.00	1	6.25	1	50.00	0	0.00	2	13.33

Table 9.8: Expectations of future care and support

Expectations of future care and support	More frequent	Less frequent
Participant describes the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	Trade or high school	University Aged 18 to 44

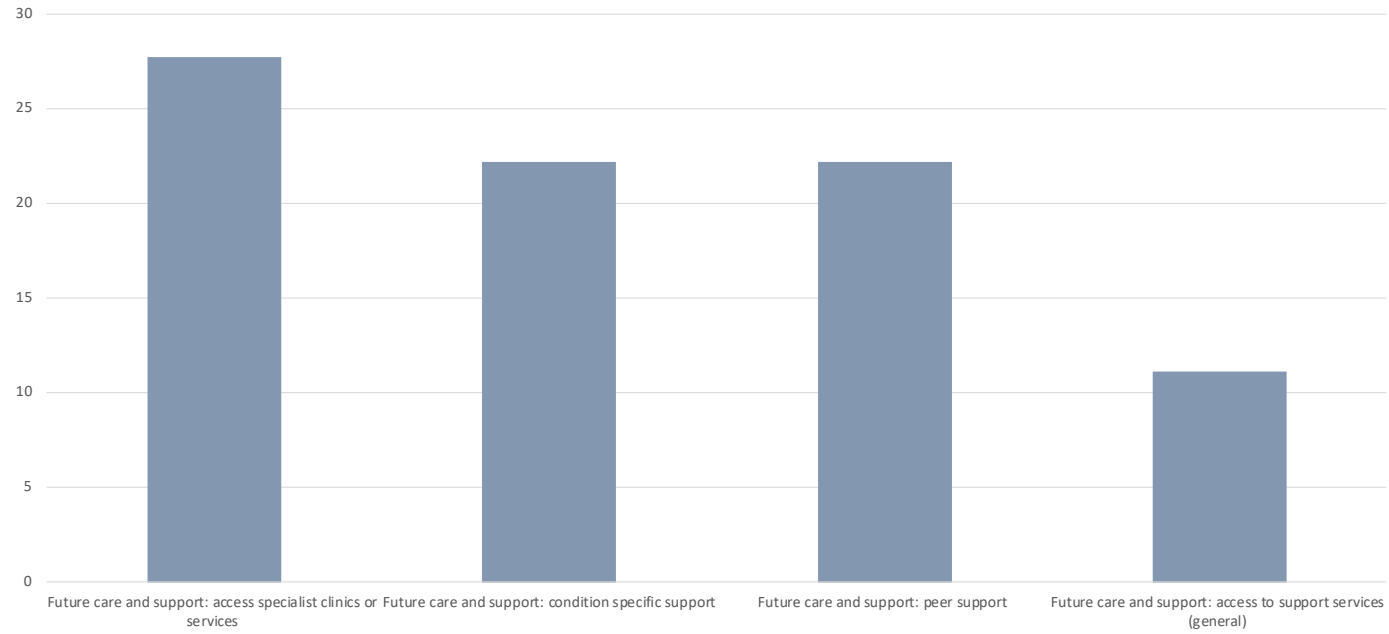

Figure 9.4: Expectations of future care and support

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was low cost/free medical care (n=6, 33.33%). This was followed by being grateful for hospitals (n=6, 33.33%).

Participant is grateful for low cost/free medical care through the government

Totally. Everything that I've had has been amazing. As in, within the hospital system and the infusions, they've been able to pay for the whole. I really can't complain with that. Participant NMO_008

Yes, I see on our Facebook group that people in America in particular, when they have a relapse, they're relying on their insurance companies to cover the cost of their meds, which are incredibly expensive, like $30,000 at a time. In Australia, I remember when we were talking immunosuppression, my neurologist said that he's assigned a piece of paper and he gets another neurologist to sign and then you get your meds. [chuckles]. That's all that it is, but which is pretty cool. I'm very, very grateful for that. Participant NMO_010

The public system just paid for it all. I'm so grateful for that. Participant NMOCA_005

Participant describes being grateful for hospitals

I've got to say that my hospital stay has been very, very good. Because I've been in hospital in LOCATION OVERSEAS, which is also very great, but I also been in LOCATION OVERSEAS, which is not so great, so I've been able to compare, and I think the whole hospital system in Australia is amazing. Participant NMO_005

Like I said, the hospitals have been really good. Participant NMO_007

Our public hospital systems are pretty damn good. Okay, some of the -- a lot of the doctors have never heard of the rare disease, but the fact that we can access the hospitals and access this care that doesn't cost us anything is a huge gift. Participant NMO_016

Participant is grateful for healthcare staff

Like I said, the hospitals have been really good. The doctors so far I've had, like NAME DOCTOR and my own GP, they've been fantastic as well. Participant NMO_007

I think the nurses need to get a bit more recognition on what they do have, because I'm saying, they're more than, obviously, the specialist and stuff, but just a caring nature, I think, is with the nurses. I think that out of all of it, it has made it more pleasant, going through what I've gone through, because they're knowledgeable. I reckon some of them are more knowledgeable than the doctors. Just saying. Participant NMO_012

The staff of that hospital are fantastic, they are dedicated health workers and I'm grateful every day I walk in there. It's not like walking into a hospital, it's like walking into a caring institution for us. Participant NMOCA_004

Participant is grateful for the entire health system

No, no, it's been perfect. We're very, very lucky here. Especially when you speak to people in the United States. Participant NMO_009

I think every single day you look at the health system in Australia, you have to be grateful for that. That is well thought out, it's a great system. Participant NMOCA_004

I think the whole hospital system in Australia is amazing. Participant NMO_005

Participant is grateful for low cost/free medical treatments through the government

The PBS. Participant NMO_014

Oh, I'm very grateful that we have Medicare, we've got the public system, I'm getting Rituximab because on the Facebook there's people in America with their insurances, and some of the treatments are refused or it's just horror stories. Participant NMO_015

I'm really, really grateful that on this health system by the way all the costs are covered. Finding out that you have something that's so rare, you don't know how it's going to affect your life, the quality of your life and then to have to worry about the cost of all the treatments, I think that would be a lot for any parent or any person that has this. Participant NMOCA_006

Table 9.9: What participants are grateful for in the health system

Aspects of the health service they are grateful for	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very goo physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant is grateful for low cost/free medical care through the government	6	33.33	3	33.33	3	33.33	3	37.50	3	30.00	3	33.33	3	33.33
Participant describes being grateful for hospitals	6	33.33	1	11.11	5	55.56	3	37.50	3	30.00	5	55.56	1	11.11
Participant is grateful for healthcare staff	4	22.22	0	0.00	4	44.44	0	0.00	4	40.00	3	33.33	1	11.11
Participant is grateful for the entire health system	3	16.67	2	22.22	1	11.11	2	25.00	1	10.00	2	22.22	1	11.11
Participant is grateful for low cost/free medical treatments through the government	3	16.67	3	33.33	0	0.00	2	25.00	1	10.00	0	0.00	3	33.33

Aspects of the health service they are grateful for	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant is grateful for low cost/free medical care through the government	6	33.33	3	30.00	3	37.50	1	16.67	5	41.67	4	57.14	2	18.18
Participant describes being grateful for hospitals	6	33.33	4	40.00	2	25.00	2	33.33	4	33.33	3	14.29	3	27.27
Participant is grateful for healthcare staff	4	22.22	4	40.00	0	0.00	2	33.33	2	16.67	2	57.14	2	18.18
Participant is grateful for the entire health system	3	16.67	1	10.00	2	25.00	1	16.67	2	16.67	1	14.29	2	18.18
Participant is grateful for low cost/free medical treatments through the government	3	16.67	1	10.00	2	25.00	2	33.33	1	8.33	0	0.00	3	27.27

Aspects of the health service they are grateful for	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 is grateful for low cost/free medical care through the government	6	33.33	3	37.50	9	34.62	5	50.00	6	37.50	0	0.00	0	0.00	6	40.00
Participant describes being grateful for hospitals	6	33.33	0	0.00	6	23.08	0	0.00	5	31.25	1	50.00	1	33.33	5	33.33
Participant is grateful for healthcare staff	4	22.22	3	37.50	7	26.92	1	10.00	3	18.75	1	50.00	1	33.33	3	20.00
Participant is grateful for the entire health system	3	16.67	2	25.00	5	19.23	1	10.00	2	12.50	1	50.00	1	33.33	2	13.33
Participant is grateful for low cost/free medical treatments through the government	3	16.67	1	12.50	4	15.38	2	20.00	3	18.75	0	0.00	0	0.00	3	20.00

Table 9.10: What participants are grateful for in the health system

Aspects of the health service they are grateful for	More frequent	Less frequent
Participant is grateful for low cost/free medical care through the government	Aged 18 to 44	Mid to low socioeconomic status Aged 45 or older
Participant describes being grateful for hospitals	More relapses Moderate to very poor physical function	Fewer relapses Good to very good physical function Aged 18 to 44

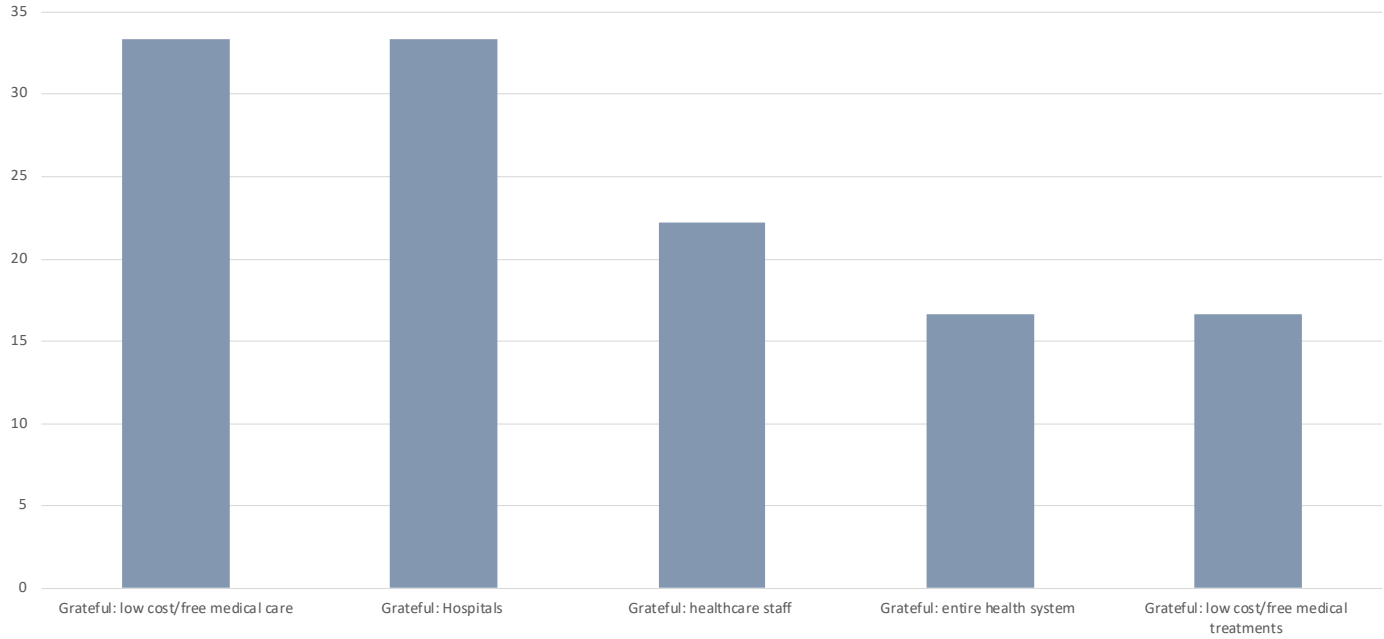

Figure 9.5: What participants are grateful for in the health system

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, were 1 is the most important and 13 is the least important. A weighted average is presented in Table 9.11, Figure 9.6. With a weighted ranking, the higher the score, the greater value it is to participants.

NMOSD

The most important aspects reported by participants with NMOSD were: weakness or paralysis of arms and legs, loss of clear vision, and loss of bowel or bladder control.

MOG

The most important aspects reported by participants with MOG were: loss of clear vision, weakness or paralysis of arms and legs, and loss of bowel or bladder control.

NMOSD or MOG

Overall, the most important aspects reported by participants with NMOSD or MOG were: weakness or paralysis of arms and legs, loss of clear vision, and loss of bowel or bladder control.

Family or carers

The most important aspects reported by participants with MOG were: loss of clear vision, weakness or paralysis of arms and legs, and eye pain.

Table 9.11: Symptoms and aspects of quality of life

Symptoms and aspects of quality of life	Participants with NMOSD (n=18)	Participants with MOG (n=8)	Participants with NMOSD or MOG (n=26)	Family or carers (n=10)
Eye pain	4.35	5.13	4.67	7.10
Loss of clear vision	6.83	7.25	6.88	8.60
Pain in spine and/or limbs	5.44	5.50	5.52	6.20
Weakness or paralysis of arms and legs	7.28	6.50	7.00	7.50
Loss of bowel or bladder control	6.83	6.00	6.56	5.30
Painful muscle spasms	4.94	3.63	4.64	4.10
Sensory loss	3.72	4.25	3.80	2.30
Prolonged hiccups	2.50	2.50	2.56	2.90
Prolonged nausea and vomiting	3.28	4.25	3.52	1.00

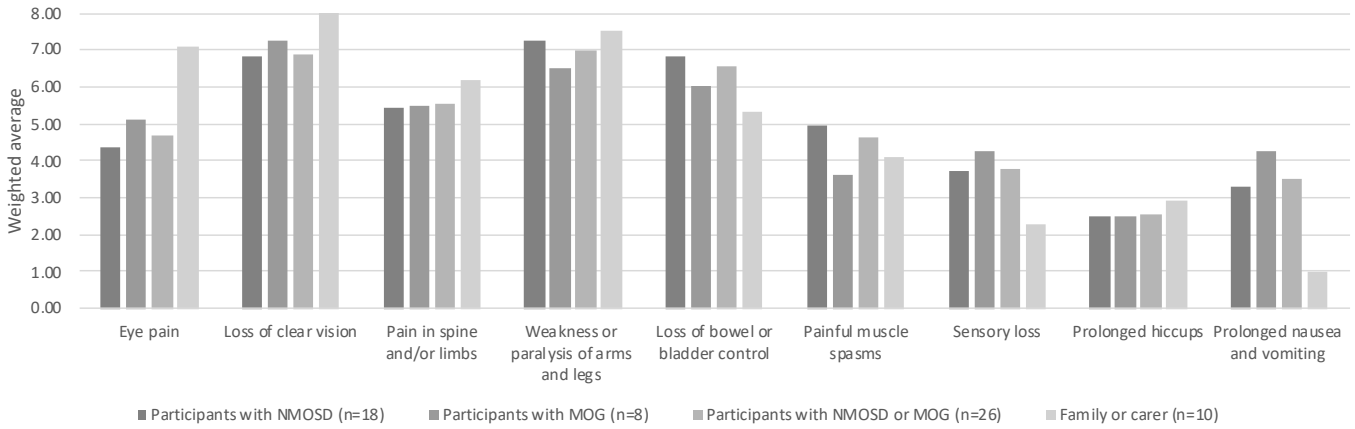

Figure 9.6: Symptoms and aspects of quality of life

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in Table 9.12 and Figure 9.7. With a weighted ranking, the higher the score, the greater value it is to participants.

NMOSD

The most important aspects to participants with NMOSD were "How safe the medication is and weighing up the risks and benefits", and "The severity of the side effects". The least important was "My ability to follow and stick to a treatment regime".

MOG

The most important aspects to participants with MOG were "How safe the medication is and weighing up the risks and benefits", and "The severity of the side effects". The least important was "The financial costs to me and my family".

NMOSD or MOG

Overall, the most important aspects to participants with NMOSD or MOG were "How safe the medication is and weighing up the risks and benefits", and "The severity of the side effects". The least important was "The financial costs to me and my family".

Family or carers

The most important aspects to family and carers were "How safe the medication is and weighing up the risks and benefits", and "The severity of the side effects". The least important was "The ability to include my family in making treatment decisions".

Table 9.12: Values in making decisions

Values in making decisions	Participants with NMOSD (n=18)	Participants with MOG (n=8)	Participants with NMOSD or MOG (n=26)	Family or carer (n=10)
How safe the medication is and weighing up the risks and benefits	7.61	7.38	7.52	7.70
The severity of the side effects	6.56	6.50	6.52	6.70
Time impact of the treatment on my quality of life	5.33	6.00	5.52	5.70
How the treatment is administered	3.89	3.63	3.92	3.30
How personalised the treatment is for me	4.33	4.50	4.36	4.40
The ability to include my family in making treatment decisions	2.72	2.88	2.76	2.50
My ability to follow and stick to a treatment regime	2.44	3.25	2.72	2.70
The financial costs to me and my family	3.11	1.88	2.68	3.00

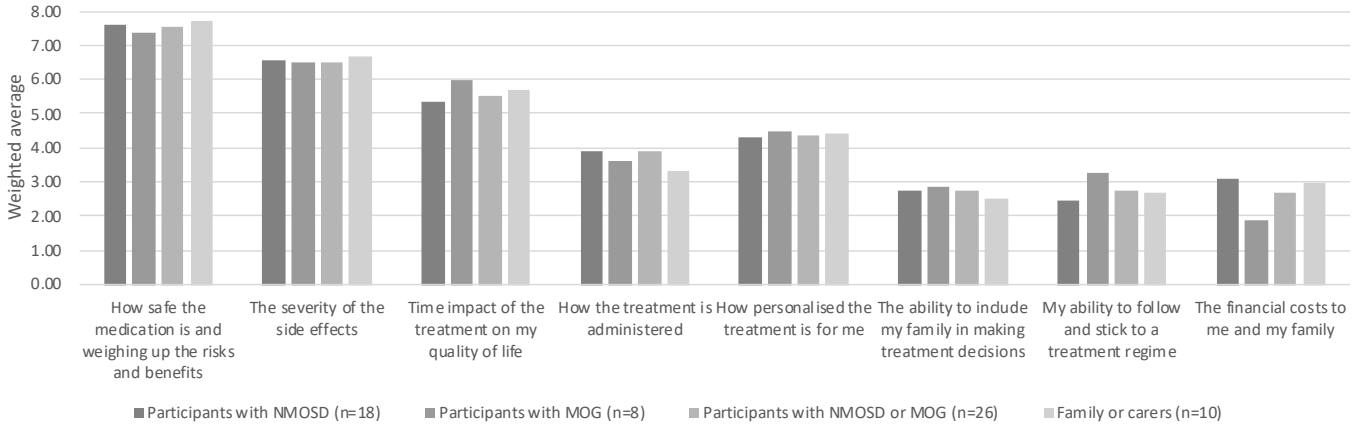

Figure 9.7: Values in making decisions

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in Table 9.13 and Figure 9.8. With a weighted ranking, the higher the score, the greater value it is to participants.

NMOSD

The two most important values for participants with NMOSD were: quality of life for patients; and access for all patients to all treatments and services; the least important was economic value to government.

MOG

The two most important values for participants with MOG were: quality of life for patients; and access for all patients to all treatments and services; the least important was economic value to government.

NMOSD or MOG

The two most important values for participants with NMOSD or MOG were: quality of life for patients; and access for all patients to all treatments and services; the least important was economic value to government.

Family and carers

The two most important values for family and carers were: quality of life for patients; and access for all patients to all treatments and services; the least important was economic value to government.

Table 9.13: Values for decision makers

Values for decision makers	Participants with NMOSD (n=18)	Participants with MOG (n=8)	Participants with NMOSD or MOG (n=26)	Family or carer (n=10)
Economic value to government and tax payers	1.33	1.50	1.40	1.20
Economic value to patients and their families	2.78	2.63	2.76	2.20
Quality of life for patients	4.22	4.38	4.24	4.80
Compassion	2.72	2.38	2.60	3.00
All patients being able to access all available treatments and services	3.94	4.13	4.00	3.80

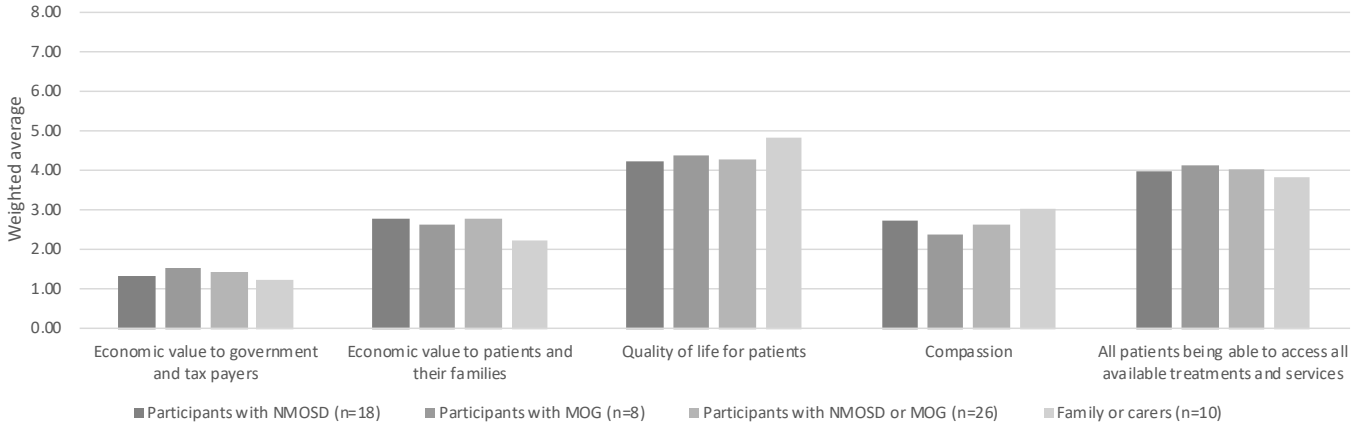

Figure 9.8: Values for decision makers

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure (Table 9.14, Figure 9.9).

NMOSD

The majority of participants with NMOSD (n=11, 64.11%) would use a treatment for more than 10 years for a good quality of life even if it didn't offer a cure. There were two participants (11.11%) that would take medication for five to 10 years, four participants (22.22%) that would take it for one to four years.

MOG

The majority participants with MOG would use a treatment for more than 10 years for a good quality of life even if it didn't offer a cure (n=5, 62.50%).

NMOSD or MOG

Overall, for participants with NMOSD or MOG, the majority of participants (n=16, 61.54%) would use a treatment for more than 10 years for a good quality of life even if it didn't offer a cure. There were three participants (11.54%) that would take medication for five to 10 years, five participants (19.23%) that would take it for one to four years, and two participants (7.69%) that would take it for less than one year.

Family and carers

Family and carers most commonly would use a treatment for more than 10 years for a good quality of life even if it didn't offer a cure (n=4, 40.00%). There were two participants (20.00%) that would take medication for five to 10 years, two participants (20.00%) that would take it for one to four years, and two participants (20.00%) that would take it for less than one year.

Table 9.14: Time taking treatment to improve quality of life

Time taking medication to improve quality of life	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG		Family or carer	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent	Number (n=10)	Percent
Less than 1 year	1	5.56	1	12.50	2	7.69	2	20.00
1 to 4 years	4	22.22	1	12.50	5	19.23	2	20.00
5 to 10 years	2	11.11	1	12.50	3	11.54	2	20.00
More than 10 years	11	61.11	5	62.50	16	61.54	4	40.00

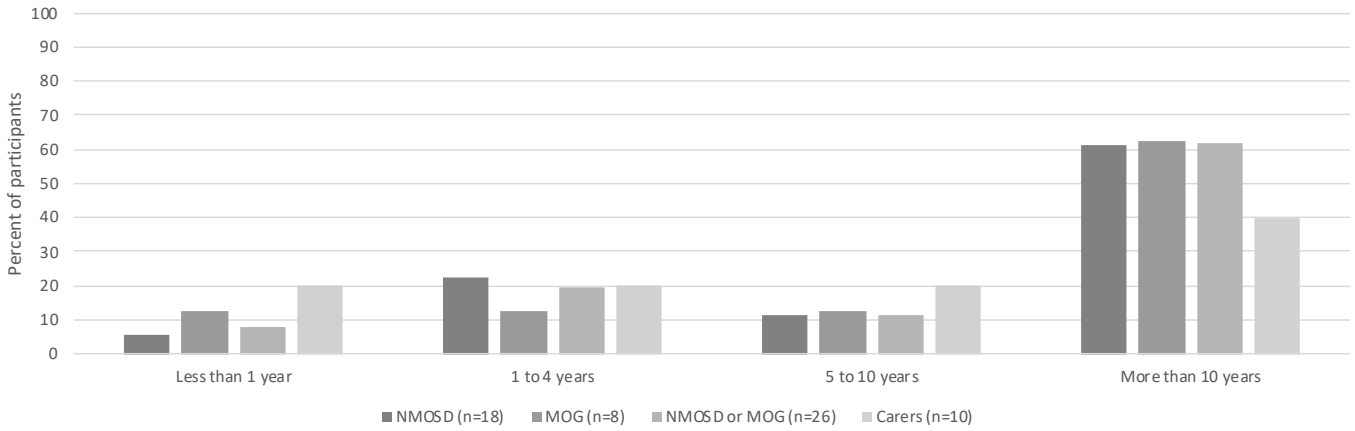

Figure 9.9: Time taking treatment to improve quality of life

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. (Table 9.15, Figure 9.10).

NMOSD

Participants with NMOSD most commonly responded that they were not sure (n=7, 38.89%), followed by IV form (n=6, 33.33%), and four participants (n=4, 22.22%) thought IV and pill forms were equally effective.

MOG

Half of the participants with MOG thought that treatment was most effective in IV form (n=4, 50.00%). There were three participants (37.50%) that thought IV and pill forms were equally effective.

NMOSD or MOG

Overall, participants with NMOSD or MOG most commonly thought that treatment was most effective in IV form (n=10, 38.46%), followed by not being sure (n=8, 30.77). There were seven participants (26.92%) thought IV and pill forms were equally effective.

Family and carers

Half of the family and carers thought IV and pill forms were equally effective (n=5, 50.00%). There were three participants (30.00%) that thought IV form was more effective, and two participants (20.00%) that were not sure.

Table 9.15: Most effective form of medicine

Treatment most effective in what form	Participants with NMOSD		Participants with MOG		Participants with NMOSD or MOG		Family or carer	
	Number (n=18)	Percent	Number (n=8)	Percent	Number (n=26)	Percent	Number (n=10)	Percent
IV form (through a drip in hospital)	6	33.33	4	50.00	10	38.46	3	30.00
In a pill form that I can take at home effective I'm not sure	1	5.56	0	0.00	1	3.85	0	0.00
I think they are equally	4	22.22	3	37.50	7	26.92	5	50.00
I'm not sure	7	38.89	1	12.50	8	30.77	2	20.00

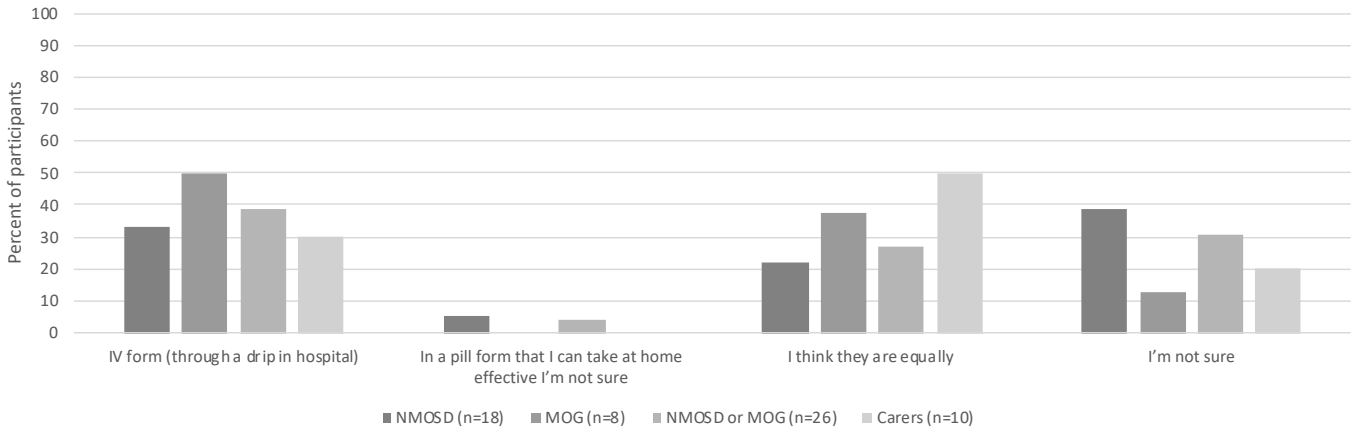

Figure 9.10: Most effective form of medicine

Messages to decision-makers

Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common message was to invest in new treatments and make them more accessible (n=7, 38.89%).

Participant's message to decision-makers is to invest in new treatments and make them more accessible

Everything that we pretty much are prescribed is off-label, so I would tell him that he needs to definitely make some things more available for us. Put some medications under the PBS, make things available. It's not always about what's cheapest, you can't always think about that. You have to think about what's best. Participant NMO_005

That there's not enough in Australia for NMO specific conditions. There needs to be more treatment options, better funding and more support, I think. Participant NMO_001

I think we need to get some of the newer drugs on the PBS and easier access for people with NMO. Participant NMO_016

Participant's message is to invest in research

I would say there needs to be more research conducted in Australia because Australia seems to be quite up there with research and development, well, except for NMO because it might actually unlock things that might lead to discoveries in other rare diseases or even MS. The fact that we've got a blood test for NMO is pretty unique when it comes to these sorts of neurological conditions. I think maybe more funding for research. Participant NMO_002

I'm sure that between all of us, we could start something to try and raise some money for research. I think that it was supposed to be a rare disease, but you can see that it's starting to increase. It's more and more people getting it, and I'd like to just get some more information about how to stop it. Participant NMO_011

My message to the Health Minister would be, just because there's not a lot of people with the disease in the country, it still warrants research money. Participant NMO_017

Participant's message is to improve access to support and care

That there's not enough in Australia for NMO specific conditions. There needs to be more treatment options, better funding and more support, I think. Participant NMO_001

It's not the same everywhere I now know. Not everybody has that 12-weeks rehab in the community. That was essential because that gave me and my family time to settle and to know that they're putting some voluntary groups in for us, putting some free hours. That is essential to anybody who is initially affected by the likes of a TM attack or NMO, that kind of thing. Participant NMO_006

People who are reeling from a life-changing situation might feel a bit better if they know that there's support out there, there is a treatment. It will change your life, there's no doubt about that, but it's the best thing that you can do at the moment and give them some hope. Participant NMOCA_004

Participant's message is to invest in professional development so that clinicians understand the condition

As a doctor in training, for example, to make this disease aware, more aware to the ones that are-- put a slot in there of what they have to learn of the NMO. What kind of GP, the specialist, all those kinds of people out there, just to know- because there's so many things of our conditions that looks like MS. That could be you just thinking that. A lot of the time, they make you feel like is this real or not with the disease. I honestly think in the doctor's training, definitely to have a slot in there for NMO in their study. Participant NMO_012

That while our public health system is good, there is not enough knowledge on NMO amongst health professionals. Participant NMOCA_002

Table 9.16: Messages to decision-makers

Message to decision-makers	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant's message to decision-makers is to invest in new treatments and make them more accessible	7	38.89	4	44.44	3	33.33	3	37.50	4	40.00	3	33.33	4	44.44
Participant's message is to invest in research (including to find new treatments)	4	22.22	2	22.22	2	22.22	3	37.50	1	10.00	2	22.22	2	22.22
Participant's message is to improve access to support and care	4	22.22	1	11.11	3	33.33	2	25.00	2	20.00	2	22.22	2	22.22
Participant's message is to invest in professional development so that clinicians understand the condition	1	5.56	0	0.00	1	11.11	0	0.00	1	10.00	0	0.00	1	11.11

Message to decision-makers	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant's message to decision-makers is to invest in new treatments and make them more accessible	7	38.89	4	40.00	3	37.50	3	50.00	4	33.33	4	57.14	3	27.27
Participant's message is to invest in research (including to find new treatments)	4	22.22	2	20.00	2	25.00	2	33.33	2	16.67	1	14.29	3	27.27
Participant's message is to improve access to support and care	4	22.22	2	20.00	2	25.00	0	0.00	4	33.33	3	42.86	1	9.09
Participant's message is to invest in professional development so that clinicians understand the condition	1	5.56	1	10.00	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09

Message to decision-makers	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's message to decision-makers is to invest in new treatments and make them more accessible	7	38.89	2	25.00	9	34.62	2	20.00	7	43.75	0	0.00	0	0.00	7	46.67
Participant's message is to invest in research (including to find new treatments)	4	22.22	1	12.50	5	19.23	2	20.00	3	18.75	1	50.00	2	66.67	2	13.33
Participant's message is to improve access to support and care	4	22.22	1	12.50	5	19.23	2	20.00	4	25.00	0	0.00	0	0.00	4	26.67
Participant's message is to invest in professional development so that clinicians understand the condition	1	5.56	2	25.00	3	11.54	2	20.00	1	6.25	0	0.00	1	33.33	0	0.00

Table 9.17: Messages to decision-makers (Subgroup variations)

Message to decision-makers	More frequent	Less frequent
Participant's message to decision-makers is to invest in new treatments and make them more accessible	Mid to low socioeconomic status Aged 18 to 44	Aged 45 or older

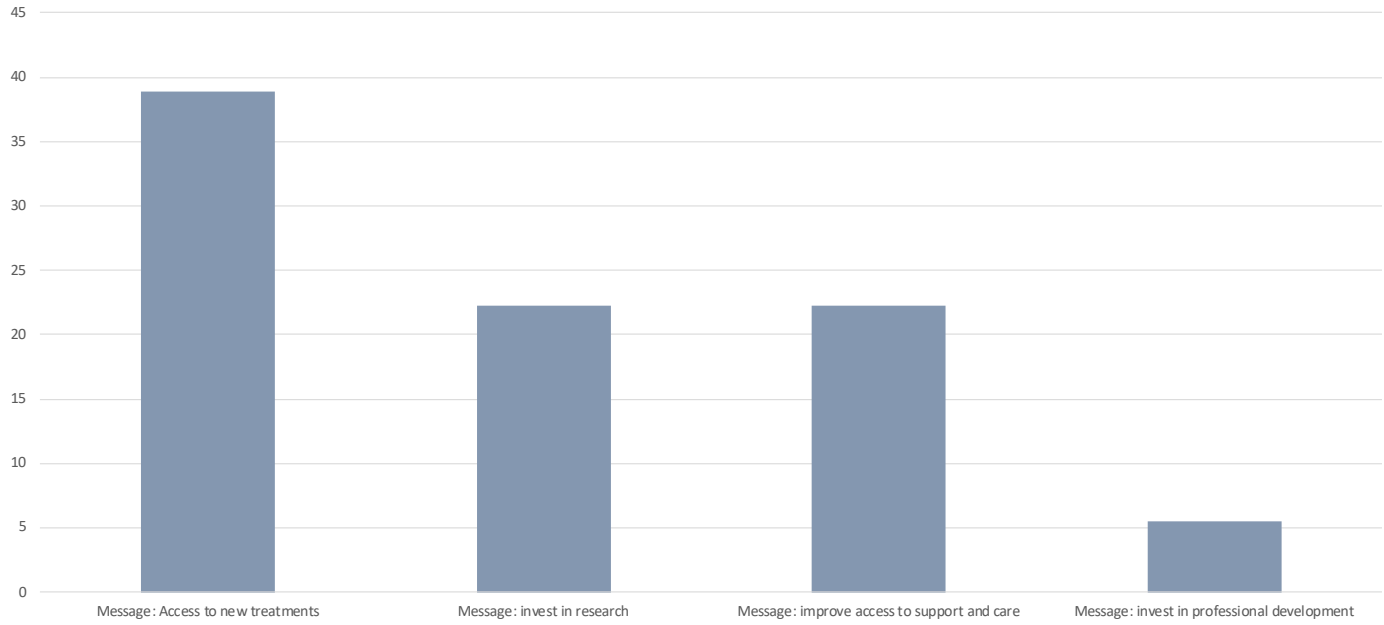

Figure 9.11: Messages to decision-makers

Section 10

Advice to others in the future: The benefit of hindsight

Wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier in relation to their condition. The two main responses were wishing they had known what to expect from their condition (e.g. symptoms, side effects of medication) (n=6, 33.33%) and wishing they had known known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration (n=6,33.33%).

Would this have influenced your decisions

Participants were asked the follow-up question "would this have influenced your decisions," the most common response was that yes this would have influenced their decisions (n=8, 44.44%).

Aspect of treatment or care they would change

In the structured interview, participants were asked if there was anything about their treatment or care they would change. The most common response from six participants (33.33%) was that they would not change any aspect of their care or treatment as they were satisfied with care and treatment received.

Wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier in relation to their condition. The two main responses were wishing they had known what to expect from their condition (e.g. symptoms, side effects of medication) (n=6, 33.33%) and wishing they had known known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration (n=6,33.33%).

Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)

I suppose everything I know now, I wish I'd have known earlier. Probably the very first time-- When I got the phone call of NMO, it would have been good if that doctor could have pointed me in a direction of some particular information rather than me-- Or even when they first sent the blood tests, and sent me for the blood test. If there was somewhere or some information he could have sent me to, instead of me having to go through the minefield of everything in the world, rather than-- Just so that there was a basic grounding of NMO rather than it being this humongous thing that some people do die of, and some people get vomiting, and some people get choking, and you're like, "What?" Just a basic information would have been good when you first get told NMO. Participant NMO_006

Yes, it was pretty grim. When I was diagnosed, they really didn't know very much. The statistics were really bad. The prognosis was particularly bad. In a way, I just thought, "Well, things are going to turn to shit in the next few years. Maybe don't bother doing-- It's just not going to be good," but that wasn't the case at all. I'm doing really well. Probably if I had a realistic picture from the beginning, it would have been better. Participant NMO_010

Definitely. I wish I had have known that this disease was actually what it was at the initial diagnosis. Participant NMOCA_007

Participant describes wishing they had known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration

Yes, definitely. I definitely would have read more after my first diagnosis online to find out that, "Hey, there are people who do regular infusion treatment, just to prevent from relapse." which I didn't know. Even though at six months, when I did the blood test, I was by then, I was like, "It's six months already, how come I'm not getting an infusion? and I asked the doctor. The doctor goes, "Oh, your antibody cell's not up yet." By the time it was nine months, I already had my relapse. I would have a pushed if I'd heard more and more people say they do regular top-ups regardless. I would have pushed for my neurologist to probably give it to me. Then maybe my relapse will be avoided, I don't know. It's hard to tell but I would have pushed, yes. Participant NMO_001

The only thing I think would have been the very first time when I went to the hospital and they sent me away. If I had have known about plasma pheresis. I had the steroids when I went back, but if I had have known about plasma pheresis, I would have asked for it sooner and I think it would have saved my eyesight because that's what did save my eyesight. I would have had both eyes I think, if it hadn't have been left for as long as it did. At the same time, I know there's so many things you can't just go in. It's very difficult. I get that, too. Participant NMO_011
Probably to take IVIG the first go. Participant NMOCA_005

Participant describes wishing they had known to ask more questions and advocate for themselves more

100%. I wish I knew how important preventing a relapse is, and I wish I knew that I should trust my own gut feeling and fight for what I think, and not always listen to doctors. That would completely change my whole illness, I think. Participant NMO_005

Yes, and also when I got the infection, I would have pushed harder to force someone to listen to me and I probably should have called in NAME's Rule because I knew I was sick, but I started to doubt myself. I started losing my confidence and I should have called, because I knew. My background is in PROFESSION and I've always worked in hospitals and stuff like that. I knew that something was wrong and I should have pushed it. Participant NMO_011

Yes. When it first all happened, I wasn't probably strong enough now that this has happened to me to push more and find out. Yes, it's quite hard because if I would have known what I know now, I could have gone to the doctor and said, "Oh, look, I know that I'm a CD19 CD20. A lot of people don't even know what CD19 and CD20 is. Virtually, yes.

The levels of what's happening, they tell you it's MS, and it's not MS. I had different things. They opened up my spine, which I wish they didn't. I think they've done damage that way. If I would have known what I know now to when it first happened, I probably wouldn't. I would have been in a different situation. Participant NMO_013

Table 10.1: Wish they had known earlier

Wish they'd known earlier	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very good physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	6	33.33	4	44.44	2	22.22	4	50.00	2	20.00	4	44.44	2	22.22
Participant describes wishing they had known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration	6	33.33	3	33.33	3	33.33	4	50.00	2	20.00	3	33.33	3	33.33
Participant describes wishing they had known to ask more questions and advocate for themselves more	4	22.22	2	22.22	2	22.22	3	37.50	1	10.00	3	33.33	1	11.11

Wish they'd known earlier	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	6	33.33	2	20.00	4	50.00	0	0.00	6	50.00	4	57.14	2	18.18
Participant describes wishing they had known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration	6	33.33	4	40.00	2	25.00	4	66.67	2	16.67	2	28.57	4	36.36
Participant describes wishing they had known to ask more questions and advocate for themselves more	4	22.22	2	20.00	2	25.00	1	16.67	3	25.00	2	28.57	2	18.18

Wish they'd known earlier	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 wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	6	33.33	3	37.50	9	34.62	3	30.00	6	37.50	0	0.00	0	0.00	6	40.00
Participant describes wishing they had known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration	6	33.33	0	0.00	6	23.08	2	20.00	5	31.25	1	50.00	3	100.00	3	20.00
Participant describes wishing they had known to ask more questions and advocate for themselves more	4	22.22	1	12.50	5	19.23	2	20.00	4	25.00	0	0.00	1	33.33	3	20.00

Table 10.2: Wish they had known earlier (Subgroup variations)

Wish they'd known earlier	More frequent	Less frequent
Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	Fewer relapses Low to moderate fear Moderate to very poor physical function University Higher socioeconomic status Aged 18 to 44	More relapses High to very high fear Good to very good physical function Trade or high school Mid to low socioeconomic status Aged 45 or older
Participant describes wishing they had known more about treatments were available and/or what treatments they should have had sooner to prevent deterioration	Low to moderate fear Mid to low socioeconomic status	High to very high fear Higher socioeconomic status

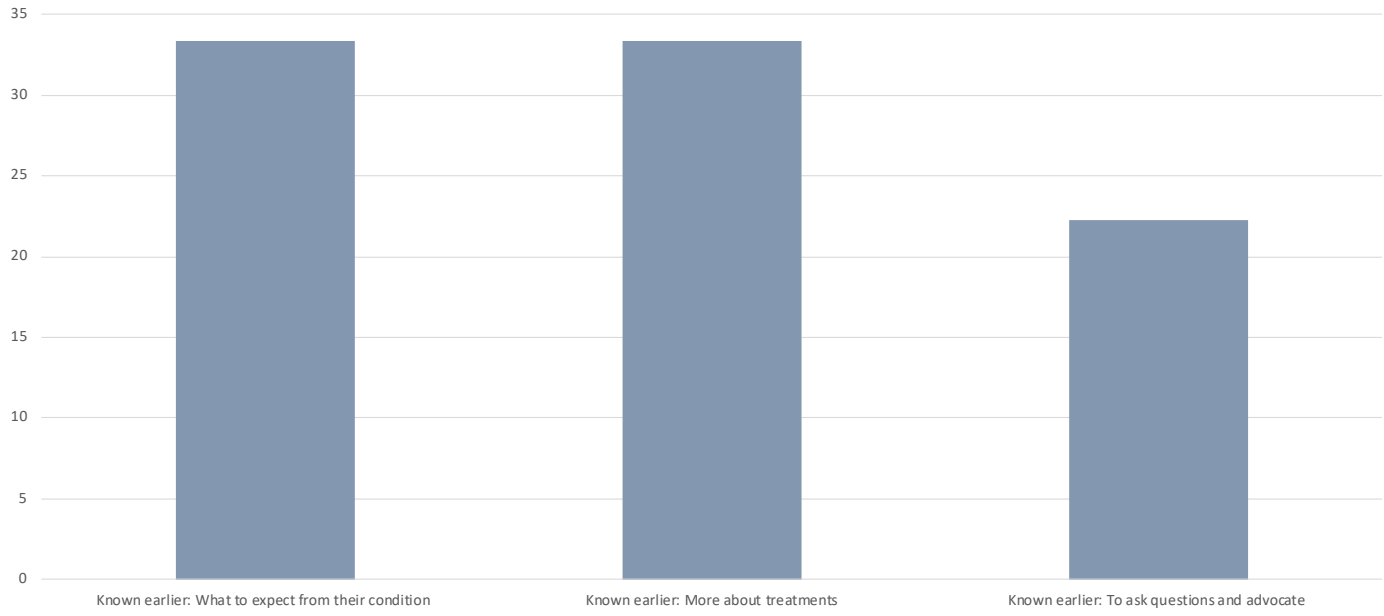

Figure 10.1: Wish they had known earlier

Would this have influenced your decisions

Participants were asked the follow-up question "would this have influenced your decisions," the most common response was that yes this would have influenced their decisions (n=8, 44.44%).

Participant feels that this would have influenced their decisions

100%. I wish I knew how important preventing a relapse is, and I wish I knew that I should trust my own gut feeling and fight for what I think, and not always listen to doctors. That would completely change my whole illness. Participant NMO_005

Yes, if I had have known about-- not that if I hadn't have known about rehab because I knew rehab was there but what things would have made it easier in the beginning to avoid the weight gain and things like that. Participant NMO_014

Definitely if we knew that she had a spinal cord injury it would have made a huge difference to knowing what services to reach out to. Participant NMO_016

Participant feels that this would not have influenced their decisions

I don't think so. Because I was focused so much on MS because I thought that's what I had, it wasn't really that much of a change in, I guess, my physical outlook for the rest of my life. I kind of already knew that I'm going to go downhill, and I kind of knew that I'll degrade. I already knew all those things, so I don't think so. Participant NMO_003

I do not think there's anything I could have that I know now. I think just supporting what I found out at the time of diagnosis and what little bit doctor specialist had told us, so I don't think it would change.. Participant NMOCA_003

No, not really. Participant NMOCA_006

Table 10.3: Would this have influenced your decisions

Would this have influenced your decisions	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant feels that this would have influenced their decisions	8	44.44	4	44.44	4	44.44	3	37.50	5	50.00	4	44.44	4	44.44
Participant feels that this would not have influenced their decisions	1	5.56	0	0.00	1	11.11	0	0.00	1	10.00	0	0.00	1	11.11

Would this have influenced your decisions	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant feels that this would have influenced their decisions	8	44.44	6	60.00	2	25.00	5	83.33	3	25.00	2	28.57	6	54.55
Participant feels that this would not have influenced their decisions	1	5.56	1	10.00	0	0.00	0	0.00	1	8.33	1	14.29	0	0.00

Would this have influenced your decisions	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 feels that this would have influenced their decisions	8	44.44	5	62.50	13	50.00	2	20.00	7	43.75	1	50.00	2	66.67	6	40.00
Participant feels that this would not have influenced their decisions	1	5.56	2	25.00	3	11.54	5	50.00	1	6.25	0	0.00	0	0.00	1	6.67

Table 10.4: Would this have influenced your decisions (Subgroup variations)

Would this have influenced your decisions	More frequent	Less frequent
Participant feels that this would have influenced their decisions	Trade or high school Mid to low socioeconomic status Aged 45 or older	University Higher socioeconomic status Aged 18 to 44

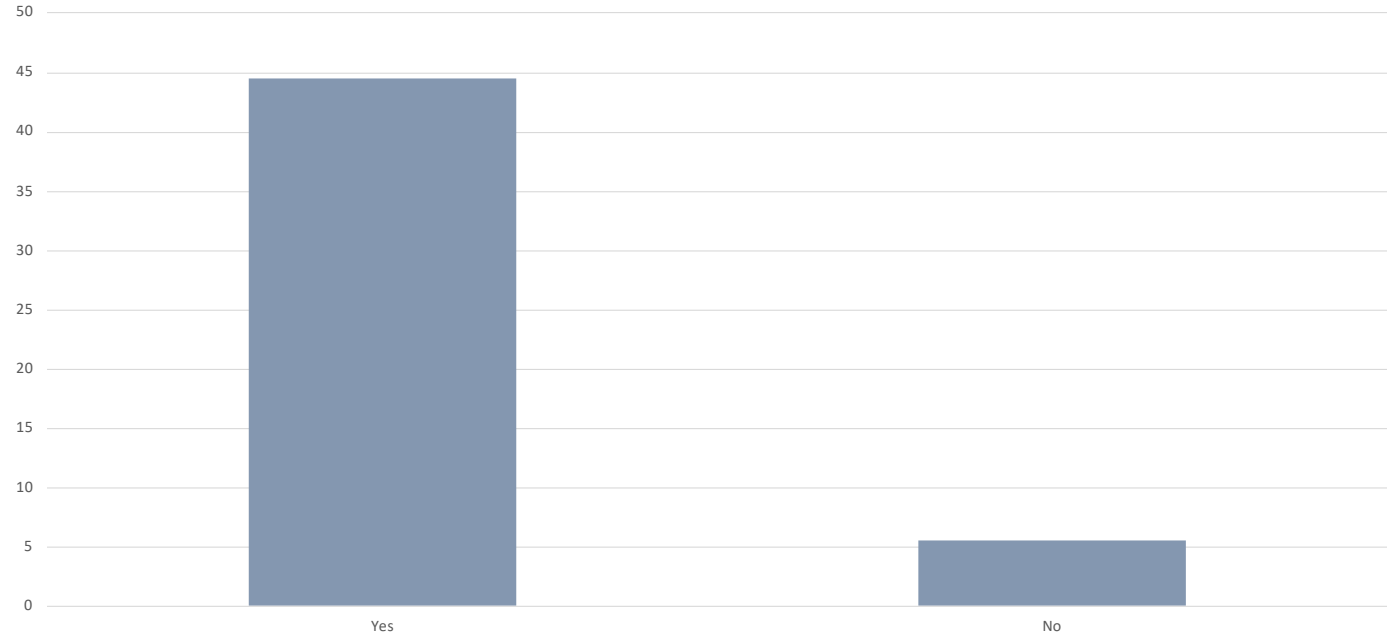

Figure 10.2: Would this have influenced your decisions

Aspect of treatment or care they would change

In the structured interview, participants were asked if there was anything about their treatment or care they would change. The most common response from six participants (33.33%) was that they would not change any aspect of their care or treatment as they were satisfied with care and treatment received.

Participant would not change any aspect of their care or treatment/satisfied with care and treatment received

I think I've been fortunate that I've had a really supportive neurologist that's head of the team and also a supportive GP. That's really all I can say. Participant NMO_004

I don't think so, because I think they did the best that they possibly knew. It was just a matter of time before this horrible aquaporin-4, or whatever, popped out of and raised its head because it was negative three times before that. It's a bit of a process, really, but they did everything. I take my hat off to them for the knowledge that they know. Participant NMO_012

At this stage right now, no. This is the first time since I've been sick where things are stable. I'm really happy with the doctors that trust me, and I love them. Participant NMO_005

Participant describes wanting to have had better communication and/or continuity of care from health professionals

Yes, just have a more accessible point of contact, I think. Participant NMO_003

Yes. That particular one of listening to the patient, that the patient needs to be listened to and needs to get taken on board. I would like to make sure that the doctors are listening properly and believing her. Participant NMO_016

Participant would not change any aspect of their care or treatment (no reason given)

No, not really, no. Participant NMO_007

No, nothing. Participant NMO_009

No. Participant NMOCA_002

Table 10.5: Aspect of treatment or care they would change

Aspect of treatment or care they would change	NMOSD		Fewer relapses		More relapses		Low to moderate fear		High to very high fear		Moderate to very poor physical function		Good to very go physical functio	
	n=18	%	n=9	%	n=9	%	n=8	%	n=10	%	n=9	%	n=9	%
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	6	33.33	4	44.44	2	22.22	4	50.00	2	20.00	2	22.22	4	44.44
Participant describes wanting to have had better communication and/or continuity of care from health professionals	3	16.67	1	11.11	2	22.22	1	12.50	2	20.00	2	22.22	1	11.11
Participant would not change any aspect of their care or treatment (no reason given)	2	11.11	1	11.11	1	11.11	0	0.00	2	20.00	2	22.22	0	0.00

Aspect of treatment or care they would change	NMOSD		Trade or high school		University		Mid to low socioeconomic status		Higher socioeconomic status		Aged 18 to 44		Aged 45 or olde	
	n=18	%	n=10	%	n=8	%	n=6	%	n=12	%	n=7	%	n=11	%
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	6	33.33	3	30.00	3	37.50	2	33.33	4	33.33	1	28.57	5	45.45
Participant describes wanting to have had better communication and/or continuity of care from health professionals	3	16.67	2	20.00	1	12.50	1	16.67	2	16.67	3	42.86	0	0.00
Participant would not change any aspect of their care or treatment (no reason given)	2	11.11	2	20.00	0	0.00	1	16.67	1	8.33	0	0.00	2	18.18

Aspect of treatment or care they would change	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 would not change any aspect of their care or treatment/satisfied with care and treatment received	6	33.33	4	50.00	10	38.46	3	30.00	6	37.50	0	0.00	1	33.33	5	33.33
Participant describes wanting to have had better communication and/or continuity of care from health professionals	3	16.67	2	25.00	5	19.23	1	10.00	3	18.75	0	0.00	0	0.00	3	20.00
Participant would not change any aspect of their care or treatment (no reason given)	2	11.11	1	12.50	3	11.54	2	20.00	0	0.00	2	100.00	1	33.33	1	6.67

Table 10.6: Aspect of treatment or care they would change (Subgroup variations)

Aspect of treatment or care they would change	More frequent	Less frequent
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	Fewer relapses Low to moderate fear Good to very good physical function Aged 45 or older	More relapses High to very high fear Moderate to very poor physical function

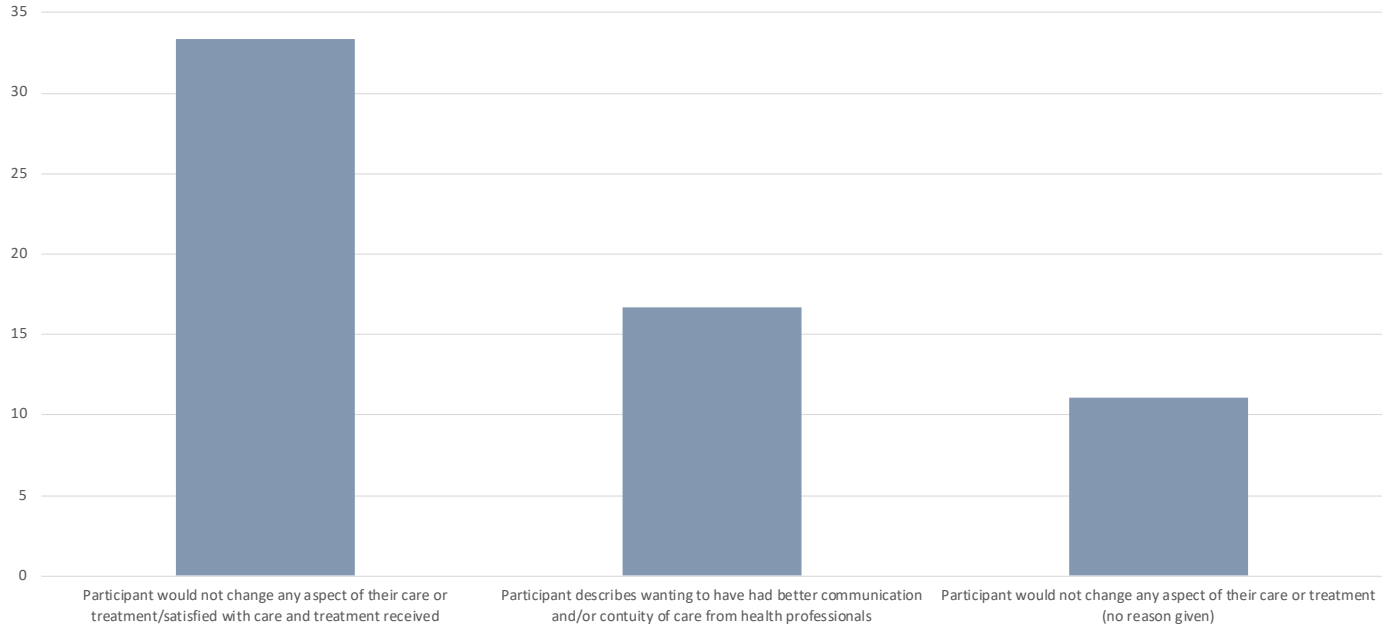

Figure 10.3: Aspect of treatment or care they would change

Section 11

Discussion

Introduction

Neuromyelitis optica spectrum disorder (NMOSD) is an autoimmune disease of the brain and spinal cord, characterised by optic neuritis (inflammation of the optic nerve) and myelitis (inflammation of the spinal cord)[1,2].

Myelin oligodendrocyte glycoprotein Antibody Disease (MOG) is an inflammatory condition that causes inflammation in the optic nerve but can also cause inflammation in the spinal cord and brain[3,4]. Previously, MOG patients may have been diagnosed with NMOSD, transverse myelitis acute disseminated encephalomyelitis, optic neuritis, or multiple sclerosis. MOG patients do not test positive for aquaporin-4 (AQP4) antibodies, and are less likely to have other autoimmune conditions[5].

In this PEEK study, there were 18 participants who diagnosed with NMOSD and 8 participants diagnosed with MOG that completed the online questionnaire and had an interview.

Incidence, prevalence and mortality statistics

NMOSD is a rare disorder previously thought to be a type of multiple sclerosis. NMOSD was difficult to distinguish from multiple sclerosis until the discovery of aquaporin 4 (AQP4 antibodies)[6]. A systematic review of reported incidence and prevalence worldwide of NMOSD reported highest estimates in Afro-Caribbean region and lowest incidence and prevalence of NMOSD were found in Australia and New Zealand[7].

Complications

Deterioration in NMOSD patients is irreversible and almost always takes place during clinical attacks[8]. Without treatment, within five years of the first attack, about half of NMOSD will be blind, and will be wheelchair users, and approximately a third will die[9]. Prognosis has improved with the identification of the AQP4 antibody[10,11]. Disabilities accumulate with relapses, it is therefore important to aggressively treat relapses and prevent relapses with maintenance therapies[12].

Risks and Symptoms

Although NMOSD can affect men and women of all ages and ethnicities, middle-aged and elderly women are most commonly affected[13]. The average age of onset is 40 years of age[14], and NMOSD is more common in African and Asian ethnicities[15,16]. Familial cases are recognised but rare[17].

Symptoms include optic neuritis (damage to optic nerve that may cause pain and temporary vision loss in one eye), acute myelitis (inflammation of spinal cord), area postrema syndrome (uncontrollable hiccups or nausea and vomiting), and narcolepsy (sleep disorder)[2].

Comorbidities

NMOSD is familial in about 3% of cases[17]. It is associated with other systemic autoimmune diseases such as thyroid autoimmunity, systemic lupus erythematosus, and Sjögren syndrome[18]. In this PEEK study, 61% that reported at least one other autoimmune disorder. Compared to healthy controls, people with NMOSD have more symptoms of anxiety and depression[19].

The most commonly reported health conditions in participants with NMOSD in this PEEK study were chronic pain (78%), sleep problems (61%), and depression either self-diagnosed or diagnosed by a doctor (50%).

Poor sleep quality in NMOSD is associated with longer illness duration, and higher fatigue[19], sleep problems were noted by 61% of NMOSD participants in this PEEK study.

There were few studies reporting co-morbidities of people with NMOSD. One study reported 45% of participants with NMOSD had mental health disorders, in this PEEK study, 61% described having either anxiety or depression (39% diagnosed by a doctor). The higher rate of anxiety and depression in this PEEK study could in part be explained by the current pandemic. Autoimmune disorders have been reported at rates of (19% to 25%)[20,21], compared to 61% in this current study. One study reported that 15% of NMOSD participants had previous malignancies[21], while no PEEK participants reported any cancer.

The National Health Survey was conducted in 2017 to 2018, it is an Australia wide survey conducted by the Australian Bureau of statistics. Almost half of the Australian population have one chronic condition%)[22]. Common chronic health conditions experienced in Australia in 2017-18 were: mental and behavioural conditions (20%), back problems (16%), arthritis (15%), asthma (11%), diabetes mellitus (5%), heart, stroke and vascular disease

(4.8%), osteoporosis (3.8%), chronic obstructive pulmonary disease (COPD) (3%), cancer (2%), and kidney disease (1%)[22]. The Australian Bureau of statistics reports that 10% of Australians have depression or feelings of depression and 13.1% have an anxiety-related condition%)[22].

Compared to the findings from the National Health Survey, the rates of chronic diseases in the PEEK NMOSD population were higher for anxiety, depression, and arthritis.

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual[23]. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

Population norms for the SF36 dimensions in Australia were assessed in the 1995 National health survey, while this was conducted 25 years ago, it can give an indication of how the PMOSD community in this PEEK study compares with the Australian population[24]. Compared to the Australian population, participants in this PEEK study on average scored lower (worse health outcomes) in all SF36 domains.

Other studies focusing on health related quality of life, have reported that the NMOSD community have physical limitations, limiting work and participation in social activities [25,26]. Physical and emotional health related quality of life scores were lower in participants with fatigue [27,28]. People with NMOSD in general scored worse compared to healthy controls, [19], and worse than people with multiple sclerosis[29], and reported lower physical function scores compared to multiple sclerosis[20].

Symptoms and disability

Symptoms include optic neuritis (damage to optic nerve that may cause pain and temporary vision loss in one eye), acute myelitis (inflammation of spinal cord), area postrema syndrome (uncontrollable hiccups or nausea and vomiting), and narcolepsy (sleep disorder)**[2].**

Other reported symptoms of NMOSD include fatigue pain, painful tonic spasms sexual dysfunction restless leg syndrome depression pruritus, and cognitive dysfunctions[25,28,30-41].

Participants with NMOSD in this PEEK study had a median of 7.5 symptoms before diagnosis, ranging from two to 12 symptoms. The most common symptoms reported in a Unite Kingdomstudy were were visual symptoms, mobility impairment, and neuropathic pain[42]. Similar patterns were seen in the current study, where loss of clear vision, eye pain, muscle spasms, and sensory loss (n=12, 66.67%) were most commonly reported. The most common symptom leading to diagnosis was visual problems, similar to another study that reported presenting symptoms as visual disturbances, numbness and/or tingling, and difficulty walking[26].

The participants in this PEEK study described what they meant by mild or severe symptoms or side effects. Mild side effects were described using the example of numbness, and neuropathic pain, and severe using the examples of pain and vison loss. Fatigue was described both as a mild and severe side effect, and in another NMOSD study, fatigue was commonly rated as being moderate to severe as it may interfere with activities of daily living [25].

Pain was common for optic neuritis[32], neuropathic pain is more severe and disabling as compared with multiple sclerosis and early involvement of a local pain team is helpful[33]. Pain may interfere with activities of daily living [25], and may contribute to fatigue[30]. Painful tonic spasm was reported in NMOSD, and was associated with a higher age at onset, and a more frequent relapse rate[34].

Diagnostic criteria

The core clinical characteristics of NMOSD are optic neuritis, acute myelitis, anti-phospholipid syndrome, brainstem syndrome, symptomatic narcolepsy or acute diencephalic syndrome with NMOSD-typical diencephalic MRI lesions, and symptomatic cerebral syndrome with NMOSD-typical brain lesions[2]. Patients that are seropositive for AQP4 require at least one core clinical characteristic for diagnosis[2]. Patients that are seronegative or unknown status for AQP4 require two core clinical characteristics with at least one of optic neuritis, ongitudinally extensive transverse myelitis, or anti-phospholipid syndrome[2].

Diagnostic tests

There is little information about standard diagnostic tests for NMOSD in Australia. The Neuromyelitis Optica Unite Kingdom Specialist Services lists the following tests used to diagnose NMOSD; medical history, MRI of brain and spinal cord, lumbar puncture, blood tests, ophthalmological examination, visual evoke potential, visual field tests, low contrast test, Ishihara test, and optical coherence tomography[43].

Participants with NMOSD reported between seven and nine diagnostic tests, with a median of six tests. Nearly all participants had blood tests, MRI of brain, optic nerves, or spinal cord, and physical examination. Most participants also had a neurologic exam, lumbar puncture and ophthalmology studies. Very few had a family history taken, or CT scans.

Biomarkers

NMOSD is classified into AQP4 antibody positive and AQP4 antibody negative diseases[44]. NMOSD includes cases of MOG-antibody-positive disease with its unique clinical spectrum that is different from AQP4-antibody positive disease[44]. NMOSD with MOG antibodies have fewer attacks and better recovery from relapses than those with AQP4 antibodies, or those that are negative for both MOG and AQP4[42,45].

Few participants with NMOSD in this PEEK study could remember having conversations about biomarker, genomic, or gene testing that might be relevant to treatment. Over 60% said they did not have these tests, yet half of the participants in the study knew their AQP4 status. This may indicate that patients need more information and discussion about biomarkers, the purpose of testing, and what the relevance of their antibody status is in terms of treatment and prognosis.

Early diagnosis and treatment is important to reduce the risk of disability and death for people with NMOSD[12,46]. A range of 29 to 43% of people with NMOSD will have had a misdiagnosis of multiple sclerosis, causing delays in preventative treatments[47,48]. In addition, some treatments for multiple sclerosis increases relapse severity and frequency, increasing disability[49,50]. Diagnostic delay has been reduced with the specificity of the AQP4 antibody, which reliably distinguishes NMOSD from multiple sclerosis[6,48,51]. In addition, the application of the International consensus diagnostic criteria for neuromyelitis optica spectrum disorders in 2015[2], has led to an increase in the diagnosis of NMOSD[52].

About a third of the participants with NMOSD in this PEEK study were diagnosed more than a year after first noticing symptoms, very few were diagnosed within a month of noticing symptoms. In addition, delays between testing and diagnosis were common. Other studies in the NMOSD community reported average time between noticing symptoms and diagnosis between one and 3.3 years[25,26].

Most participants in a United Kingdom study described having difficulty with getting an NMOSD diagnosis. This was mostly due to misdiagnosis with multiple sclerosis[42]. Over a quarter of participants with NMOSD in the current study were misdiagnosed with multiple sclerosis, contributing to the delay with an NMOSD diagnosis.

Relapse

A relapse, or an attack of NMOSD, occurs when there is inflammation within the nervous system, attacks commonly include transverse myelitis optic neuritis, but can also include area postrema syndrome, and brainstem syndrome, or combinations of any of these[53]. People with NMOSD that have MOG antibodies have fewer attacks and better recovery from [42,45], relapse rates have been reported to be higher in African ethnicity, children and in those of shorter disease duration[54].

About a third of the participants with NMOSD in this PEEK study had one or two relapses, and about a third had three or four relapses. Physical disability was measured in this study in the SF36 physical function, and role functioning/physical domains, however, no differences were seen between those that had fewer than two relapses and those that had more.

Support at diagnosis

Almost all participants in this PEEK study felt that they either had no support or not enough support at diagnosis, similar to another study in an NMOSD population that reported participants wanted more support than they had received, especially during the early stage of diagnosis[42].

Decision making

The decision-making process in healthcare is an important component in care of chronic or serious illness[55]. Knowledge of prognosis, treatment options, symptom management, and how treatments are administered are important aspects of a person's ability to make decisions about their healthcare[56,57] highlighting the importance of healthcare professional communication.

Important aspects of health-related decision making for the participants in the current study were side effects, efficacy, and cost. Approximately a third of participants felt they did not have the opportunity to take part in decision making for the treatment and management of their condition, and only about 20% of participants felt they played an active role in decision making. The participants displayed a willingness to take part in decision making when it comes to deciding how their condition is managed, especially as they feel more informed and assertive, and are aware of their own health and limitations

In addition, the role of family members in decision making is important, with many making decisions following consultation with family[58]. In the current study, participants with NMOSD did not discuss the role of their family in decision making, however, 30% of family and carers discussed taking an active role.

Treatment

Acute treatment of an NMOSD attack consists of high dose steroids for five days, oral prednisolone then continues for weeks, reducing over the course of months. Plasma exchange is used when improvement is not seen within days of high dose steroids [12,23]. Plasma exchange has been shown to be more effective in improving recovery following relapse compared to high dose steroids, suggesting that escalation to plasma exchange may reduce long term disability in NMOSD**[23,59].**

All participants with NMOSD in this PEEK study had IV high dose steroids, nearly all had side effects, and on average quality of life on high dose steroids was low. However, on average, they rated this treatment as effective.

Less than half of the participants with NMOSD in this PEEK study had plasma exchange, about a quarter reported no side effects from this treatment. Quality of life from the treatment was low, but participants rated it as very effective.

Progression of neurological disability in NMOSD is thought to mainly occur during clinical attack/relapse[9], suggesting that preventing clinical attacks is the most important therapeutic target in NMOSD[8]. Management of NMOSD consists of preventative immunotherapy treatment, monitoring safety of treatment and adherence to treatment[18]. Immunosuppressive treatments reduce but do not stop relapses, however, they may reduce the disabling effects of optic neuritis and transverse myelitis[54]. Relapse prevention therapy is recommended for all patients that are AQP4 positive, and for AQP4 negative patients with established relapsing disease[60]. Following relapse, it is recommended to switch to a drug with a different mechanism of action, combination therapy is an option but data is limited[18]. Disease modifying drugs used in multiple sclerosis have been shown to with not work in NMOSD or may exacerbate NMOSD and should be avoided [61-63]

The most common prevention therapies used include azathioprine, mycophenolate mofetil and rituximab resulting in relapse free rates of between 25% and 66%[64-69]. Oral prednisolone is often given long-term, as the combination may be more protective than mycophenolate mofetil or rituximab alone[70]. Other immunosuppressants that are occasionally used include tocilizumab, methotrexate, cyclophosphamide, mitoxantrone, intravenous immunoglobulins, tacrolimus, and ciclosporin[70].

All participants with NMOSD in the current study had taken at least one long term treatment for the management of their condition. The most common types were rituximab, and prednisone. Most participants had side effects from prednisone, and reported low quality of life, however, on average found the treatment effective. Almost half of the participants taking rituximab reported no side effects, quality of life was rated as average. Peek participants rated rituximab as effective, which has been reported elsewhere[26].

Allied health

There is little published information about the use of allied health to manage NMOSD. In this PEEK study, 61% of participants with NMOSD used at least one allied health service in the management of NMOSD. As NMOSD is a progressively disabling condition, there is a gap in services for this cohort. The most common allied health services were occupational therapy (56%), physiotherapy (50%) and psychology

(44%), participants found these moderately effective to effective.

Lifestyle changes

There is little published information about lifestyle changes in the NMOSD community. In the current study, 83% of participants with NMOSD made at least one lifestyle change, most commonly exercise, and diet changes. Exercise was used by participants for both their mental health and physical health. Information about lifestyle changes was not given to many participants, one participant was given information about exercise, and no participants given information about diet. More than half of the NMOSD participants searched independently for information about diet and/or exercise. There is clearly interest in lifestyle changes for the management of NMOSD, and a need for more information.

Complementary therapies

There is little published data about complementary therapies in the NMOSD community. In this PEEK study, over 75% used at least one type of complementary therapy, the most common types were mindfulness or relaxation techniques, supplements, and massage therapy. Participants were given no information about complementary therapies, yet over 60% searched for information independently. More discussions are needed in this area so that people with NMOSD can safely use complementary therapies alongside their other treatments.

Clinical Trials

Clinical trials are essential for development of new treatments. The benefits to participants include access to new treatments, an active role in healthcare, and closer monitoring of health condition. The risks to participants include new treatment may not be as effective, and side effects.

A search of the Australian New Zealand Clinical Trials Registry was conducted on 9 February 2021. The search included any study that included NMOSD participants, was conducted in Australia, and began recruitment at any time. A total of four studies were identified that had a target recruitment of between 56 and 231 participants, all studies were international studies with Australian sites in NSW or Victoria. Currently, only one study is recruiting.

In this PEEK study, very few had discussions with their doctor about clinical trials, and no participants had taken part in a clinical trial for NMOSD. However, there is a wiliness to take part in a clinical trial (89%).

Patient treatment preferences

Clinical guidelines that are aligned to patient preferences are more likely to be used and lead to higher rates of patient compliance[71-73]. Patient preferences and priorities vary across different health issues[71], preferences are associated with health care service satisfaction, they refer to the perspectives, values or priorities related to health and health care, including opinions on risks and benefits, the impact on their health and lifestyle[71,74].

To help inform patient preferences in the NMOSD community, participants discussed side effects, treatment administration, adherence to treatment Participants were asked to describe what a mild side effect was. Some participants described side effects using specific examples such as numbness/paraesthesia, or neuropathic pain. Others described mild side effects as those that do not interfere with their daily life. In a similar way, participants describe severe side effects either as those that impact daily life, and using examples or severe side effects such as pain and vision loss. Discussing both a list of side effects and the potential impact on daily life may be important for treatment decision making.

When discussing adhering to treatments, there were those that would continue as long as side effects are tolerable, others described never giving up on treatments, while some described adhering to treatment on advice of their doctor. Participants described changes needed for them to feel like a treatment was working, most commonly reduction in a specific symptom, improvements in pain, prevention of relapse and improved mobility. Treatment adherence may be improved by discussing expected side effects and mechanisms and support to manage side effects. In addition to discussing the clinical aspects of treatment goals, discussing other aspects such as symptom reduction and weather improvements should be expected in current disabilities may improve adherence by setting expectations of signs that the treatment is working.

Affordability of healthcare

Almost half of the Australian population have private health insurance with hospital cover[75]. This can be used to partially or completely fund stays in public or private hospitals. Between 2006 and 2016, the proportion of private health care funded hospitalisations in public hospitals rose from about 8% to 14%[75]. In this PEEK study, 61% had private insurance, which is more than the Australian population. It should also be noted that participants in this study were grateful for the low cost medical care and access to treatment and hospital through Medicare.

Self-management

Self-management of chronic disease encompasses the tasks that an individual must do to live with their condition. Self-management is supported by education, support, and healthcare interventions. It includes regular review of problems and progress, setting goals, and providing support for problem solving[76]. Components of self-management include information, activation and collaboration[76].

Patient activation is measured in the PEEK study using the Partners in Health questionnaire[77]. The NMOSD participants in this study had good scores for knowledge, , recognition and management of symptoms, very good scores for adherence to treatment, and moderate scores for coping.

Information is a key component of health self-management[78,79]. The types of information that help with self-management includes information about the condition, prognosis, what to expect, information about how to conduct activities of daily living with the condition, and information about lifestyle factors that can help with disease management[78,79].

The most common types of information given to participants in this PEEK study were about treatment options, and disease management, however, about a third of the participants had little to no information given to them by their healthcare professionals.

The type of information that participants in this PEEK study searched for independently most often were disease management, disease cause, complementary therapies, and treatment options. Half of the participants looked for information about dietary information, and physical activity.

Regarding access to information, participants in the PEEK study had prefered online information, speaking to someone or a combination of both. In this study, participants with NMOSD looked for information on the internet in general, on Facebook, and through the Guthy-Jackson Foundation. Journal articles, treating clinician and other patient's experience were noted as important to some. In terms of timing of information, again, PEEK participants benefited from information at different times, from the time they were diagnosed, sometime after diagnosis

Activation (skills and knowledge)

Patient activation is the skills, knowledge, and confidence that a person has to manage their health and care; and is a key component to health self-management. Components of patient activation are support for treatment adherence and attendance at medical appointments, action plans to respond to signs and symptoms, monitoring and recording physiological measures to share with healthcare professionals, and psychological strategies such as problem solving and goal setting.

Communication and collaboration

Collaboration is an important part of health self-management, the components of collaboration include healthcare communication, details for available information, psychosocial and financial support[78,79]. Communication between healthcare professionals and patients can impact the treatment adherence, self-management, health outcomes, and patient satisfaction[80-83].

An expert panel identified the fundamental elements of healthcare communication that encourages a caring, trusting relationship for patient and healthcare professional that enables communication, information sharing, and decision-making[84]

Building a relationship with patient, families and support networks is fundamental to establishing good communication[84]. Healthcare professionals should encourage discussion with patients to understand their concerns, actively listen to patients to gather information using questions then summarising to ensure understanding[84]. It is important for healthcare professionals to understand the patient's perspective and to be sympathetic to their race, culture, beliefs, and concerns. It is important to share information using

language that the patient can understand, encourage questions and make sure that the patient understands[84]. The healthcare professional should encourage patient participation in decision-making, agree on problems, check for willingness to comply with treatment and inform patient about any available support and resources[84]. Finally, the healthcare professional should provide closure, this is to summarise and confirm agreement with treatment plan and discuss follow up.

In interviews with 15 participants with NMOSD from the United Kingdom, a common theme of negative encounters with healthcare professionals was reported. This was mostly due to a lack of knowledge, resulting in treatment delays[42]. Similarly, most participants with NMOSD in the current study had a negative experience of communication with healthcare professionals. This was because health care professionals had limited understanding of NMOSD, dismissive, or just very limited.

Positive communication in this PEEK study, was usually a result of a two-way supportive and comprehensive conversation between patient and clinician. This was also reported in another study, where participants appreciated honesty alongside health professionals listening to their needs[42].

Communication and collaboration with healthcare professionals was measured in this PEEK study by the Care Coordination questionnaire[61,85]. Participants had moderate scores for navigation of the healthcare system, and they rated their overall care as good, coordination of care as moderate. They had a poor score for communication with healthcare professionals.

Quality of life

NMOSD has a negative effect on quality of life[27,29], fatigue and pain have a negative impact on daily activities[26,28,33,86-88], and depression and anxiety have an impact on physical and emotional health[27,28,86,89].

Most participants with NMOSD in this PEEK study reported an overall negative impact on their quality of life due to their condition. The main reasons for this were changes in relationships, reduced physical activity, social interactions, anxiety about prognosis, fatigue and disability.

Almost all participants in this PEEK study reported that NMOSD had an impact on their mental health. The regular activities to maintain mental health were, physical exercise, mindfulness, consulting a mental health professional, remain engaged in social activities and hobbies.

Participants used physical activity to maintain both their mental and physical health. Other ways that participants in this PEEK study maintained their health was to understand their limitations, self-care, and treatment compliance. Similar to another study of NMOSD participants that described ways of dealing with fatigue, and needing to pace themselves[42].

Having NMOSD impacted relationships for participants in this study. Relationships were impacted because of difficulty in socialising and others withdrawing from relationships. Many NMOSD participants described being a burden on their family, mostly because family members had to take on extra responsibilities, and assist with getting to appointments. This is similar to another study that reported frustrations in having to depend on others due their physical limitations, and the difficulties in friendships due to ignorance of NMOSD, and difficulties socialising[42].

Anxiety associated with condition

In this PEEK study, anxiety associated with NMOSD was measured by the fear of progression questionnaire[90]participants in this study had high levels of anxiety concerning disease progression. The greatest concerns were about disease progression, reaching professional or personal goals, relatives being diagnosed with disease, being able to pursue hobbies, treatment will damage body, worried about family if anything happens to them, and not being able to work. In addition, themes from the structured interviews included reduced quality of life due to limitations on social interactions, and the inability to complete activities of daily living. This is similar to other studies, where NMOSD participants reported being fearful of relapse, symptom progression, changes to life plans, ability to complete daily activities and engage in social activities[26,42].

Characterisation

There were 18 participants with NMOSD, eight participants with MOG and 10 people who cared for people with NMOSD or MOG, in the study from

across Australia. This characterisation of the study will focus on participants with NMOSD. The majority of participants lived in major cities, they lived in all levels of economic advantage. Most of the of participants identified as Caucasian or white, and were aged mostly between 45 and 64. Under half of the participants had completed some university, and less than a third were employed either full time or part time. Less than a third of participants were carers to family members or spouses.

Participants in this PEEK study most commonly had between two and four relapses, and were diagnosed after they turned 40. This patient population was also characterised by comorbidities with an average of four other conditions in addition to NMOSD. More than half of the participants had chronic pain, sleep problems, or depression.

This is a patient population that sought medical attention relatively soon after noticing symptoms The most common symptoms before an NMOSD diagnosis were loss of clear vision, eye pain, muscle spasms, and sensory loss, causing a poor quality of life. Visual problems was the symptom that most often led to a diagnosis.

On average, this group had six diagnostic tests for their condition, they were diagnosed by a neurologist at hospital. They were most commonly diagnosed after being admitted to the emergency department or hospital. They didn't have enough emotional support or enough information at diagnosis. This is a cohort that did not have conversations about biomarker, genomic, or gene testing, but were able to recall having had this type of test.

This is a study cohort that knew nothing or very little about their condition at diagnosis. They commonly associated the condition with multiple sclerosis and poor prognosis, often describing their prognosis in relation to the long-term permanent effects they have suffered from it.

This is a patient population that mostly had discussions about multiple treatment options, some participated in the decision-making process while others did not. The most common specific treatment discussed was rituximab.

This is a study cohort that considered the side effects, efficacy and costs when making decisions about treatment. The participants felt that the way they made decisions had changed over time because they had become more informed or assertive.

When asked about their personal goals of treatment or care, participants wanted to maintain their condition, and prevent relapses.

This is a group who felt that throughout their experience, they were treated with respect , with the exception of one or two occasions. They were all cared for by a neurologist.

This is a cohort that had private health insurance that were often treated as public patients in public hospitals. They had no problems with paying for healthcare appointments, filling prescriptions, paying for basic essentials. The monthly out of pocket spending for NMOSD wasn't usually a significant burden.

Participants in this study had to quit their job, though carers and family did not have to change employment status. The loss of income due to NMOSD was a burden on many participants.

All participants had been treated with high dose steroids, while this was found to be effective, the quality of life was low. The most common immunosuppressant taken was rituximab, about half had no side effects from rituximab, participants found this treatment effective.

There were very few conversations about clinical trials, however, they would take part in a clinical trial if there was a suitable one for them.

This is a patient population that described mild side effects using examples like numbness or paresthesia, and neuropathic pain. They also described severe side effects using examples, such as pain, or vision loss.

Within this patient population, participants adhered to a treatment plan as long as side effects were tolerable. This is a study cohort that needed to see a reduction in a specific symptoms in order to feel that treatment is working as well as needed to see an improvements in pain levels.

Participants preferred to have treatment at home rather than in hospital because it was more comfortable and convenient, with less interruption to daily life. Participants in this study would need to be checked regularly by a GP or nurse at home if they

were having treatment at home to ease their anxiety.

This study cohort largely had some access to allied health services the most common being occupational therapists, physiotherapists, and psychologists. They found that services from allied health were generally effective.

Almost all participants made lifestyle changes to help manage their NMOSD, they usually exercised or made diet changes. They also tried complementary therapies to help manage their condition.

This participant population largely did not have access to telehealth services. Access was usually due to COVID-19, and those who used telehealth were pleased with their experience.

Within this patient population, it was most commonly felt that if treatment worked it would allow them to engage more with social activities and family life.

Participants in this study had good knowledge about their condition, were good at recognizing and managing symptoms, were excellent at adhering to treatment, and were average at coping with their condition,

Participants weren't given a lot of information about NMOSD. They were mostly given information treatment options, and disease management. Participants searched for information about many aspects of NMOSD including disease management, disease causes, treatment options, complementary therapies, and physical activity. This is a group who accessed information from non-profit, charity or patient organisations most often.

This is a patient population that accessed information through the internet, Facebook and the Guthy-Jackson Foundation. There was no information that wasn't helpful, but they found other people's experiences especially helpful.

This is a group that preferred to get their information online, talking to someone, or a mixture of both. They generally felt most receptive to information from the beginning, at diagnosis, or wanted to wait a bit after diagnosis to be given information.

Participants had a negative experience of communication when the healthcare profession had limited knowledge about NMOSD. They had positive experience of communication when conversations with healthcare professionals were two-way, supportive and comprehensive.

The participants in this study experienced good quality of care, and average coordination of care. They had an average ability to navigate the healthcare system, and experienced poor communication from healthcare professionals.

This is a patient population that most commonly did not receive care and support, though when they did, it was mainly through domestic services, for transport and from a hospital or clinical setting.

This is a patient population that experienced a negative impact on quality of life generally due to emotional strain on family/change in relationship dynamics and reduced capacity for physical activity. Emotional strain on family and changes in relationship dynamics had a negative impact on quality of life, as did the reduced capacity for physical activity

This is a study cohort that experienced at least some impact on their mental health and to maintain their mental health they exercised or used mindfulness techniques and meditation.

Within this patient population, participants described the importance of being understanding of their limitations, and practising self-care in order to maintain their general health.

This cohort most commonly felt there was a negative impact on their relationships due to having difficulties socialising.

This patient population felt their condition was a burden on their family, usually it was because of the extra household duties or responsibilities their family had to take on, and being taken to appointments.

Most participants felt there was some cost burden which was primarily in relation to time off work, and the cost of treatments.

The participants in this PEEK study had high levels of anxiety in relation to their condition, and overall, NMOSD had a negative impact on quality of life.

Participants would like future treatments to have fewer or less intense side effects, for there to be

more options to treat NMOSD, and more affordable treatments.

This is a study cohort that would like more information that is specific to NMOSD, and information about where to find services.

Participants in this study would like future communication to be more transparent and for healthcare professionals to be more forthcoming with information. They would like specialist clinics or services for NMOSD where they can talk to professionals, either in person, online or by telephone.

This patient population was grateful for healthcare staff, the entire health system, and low cost or free medical care through the government.

It was important for this cohort to control weakness or paralysis of arms and legs, loss of clear vision, and loss of bowel or bladder control. Participants in this study would consider taking a treatment for more than ten years if quality of life is improved with no cure.

Participants in this study valued knowing the safety of medication, and side effects when making treatment decisions, and thought that the government should consider the quality of life of patients when making decisions that impact treatment and care.

The message to decision-makers given by participants in this study was to invest in new treatments and make them more accessible. They would like more NMOSD research, and better access to support and care.

This is a patient population that wished they had known what to expect from their condition, the treatments available to prevent attacks, and they wish they had known to ask more questions and advocate for themselves.

Most participants in this cohort would not change their care and treatment primarily because they were satisfied with the care they received, though there were some that would have liked better communication and continuity of care.

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Section 12

Next steps

Next steps

At the end of each PEEK study, CCDR identifies three key areas that, if improved, would significantly increase the quality of life and/or the ability for individuals to better manage their own health.

In relation to this community, these three areas are:

1. **Information:** Throughout the study, participants noted the difficulties in finding local, disease-specific information. This patient population would benefit from an Australian website with transparent and forthcoming information about what NMOSD is, as well as current and emerging treatments. This may be complemented by an annual or biennial conference updating the community on current research and treatments.

2. **Health system navigation:** Once diagnosed with NMOSD, there is complex health system that needs to be navigated to ensure patients are accessing allied health and supportive care. This patient population would benefit from the development of a 'Health System Navigation' kit, so that they can anticipate the services that they may need in the future and how to access them.

3. **Symptom tracking and monitoring:** A recurring theme within the study was the importance of avoiding relapse and maintaining current health and independence. This patient population would benefit from the development of bespoke symptom tracking tools so that they can monitor their ability to function over time and recognise changes so that they can access timely or early medical or therapeutic interventions.

2020 NMOSD

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2020 metrics that the sector can work together to improve upon are provided in Table 12.1

Table 12.1 NMOSD 2020 Metrics

Measure	Detail	Mean	Median
Baseline health (SF36)	Physical functioning	53.61*	62.50
	Role functioning/physical	30.56	0.00
	Role functioning/emotional	31.48	0.00
	Energy/fatigue	28.33*	27.50
	Emotional well-being	57.56*	62.00
	Social functioning	47.92*	50.00
	Pain	43.06*	45.00
	General health	32.78*	32.50
	Health change	43.06	37.50
Knowledge of condition and treatments (Partners in Health)	Knowledge	23.00*	22.00
	Coping	11.50*	11.50
	Recognition and management of symptoms	17.72*	19.00
	Adherence to treatment	12.89*	12.50
	Total score	65.11*	62.50
Care coordination scale	Communication	30.94	29.50
	Navigation	20.56*	21.50
	Total score	51.50*	52.00
	Care coordination global measure	5.67*	6.00
	Quality of care global measure	6.00	6.00
Fear of progression	Total Score	41.33*	41.50
		Percent	
Accessed My Health Record	-	50.00%	-
Participants that had discussions about biomarkers/genetic tests	-	27.78%	-