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 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.

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.

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.

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%).

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 (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.

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)

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%).

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%).

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%).

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.