# MULTIFOCAL MOTOR NEUROPATHY AND CHRONIC INFLAMMATORY DEMYELINATING POLYRADICULONEUROPATHY PATIENT JOURNEY AND EXPERIENCE: A QUALITATIVE STUDY

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### INTRODUCTION

- Multifocal motor neuropathy (MMN) and chronic inflammatory demyelinating polyradiculoneuropathy (CIDP) are rare neuromuscular diseases characterized by muscle weakness with or without sensory loss<sup>1, 2</sup>
- The diagnosis of these diseases can be challenging, often leading to delayed and inaccurate diagnoses, which places a substantial burden on patients, and is associated with worse prognosis<sup>1, 3</sup>
- Common misdiagnoses include monomelic amyotrophy, Guillain-Barré syndrome, or amyotrophic lateral sclerosis<sup>2</sup>

## OBJECTIVES

- To describe the patient experience of both MMN and CIDP, including the diagnostic and treatment journey, burden of illness, and communications with physicians related to diagnosis and disease management
- To identify unmet needs related to care of MMN and CIDP

## METHODS

- In the first phase of this observational, qualitative study, adult patients in the United States with MMN or CIDP participated in 60-minute semi-structured interviews by web-based teleconferencing
- Survey questions aimed to:
- Assess the effect of MMN or CIDP conditions on quality of life (QoL)
- Characterize patients' experience with immunoglobulin (IG) treatments
- Evaluate barriers and gaps in care
- Understand shared decision-making and communication with care teams
- Interviews were recorded and subsequently transcribed
- Transcripts were reviewed to identify and code common themes relative to the discussion topics

## RESULTS

- Between March 21, 2023, and April 13, 2023, 10 patients (MMN = 6; CIDP = 4) were interviewed
- Most were women (n = 7), aged 45–64 years (n = 6), living in the Northeastern United States (n = 4), with a postgraduate degree (n = 6), and access to commercial health insurance (n = 6)
- The following 5 key themes emerged from the interview responses:





• Patients experienced symptoms and visited multiple physicians from less than a year to over a decade prior to receiving a diagnosis (Figure 1)



computerized tomography; EMG, electromyography; MRI, magnetic resonance imaging.

- misdiagnoses
- reminder of their disease
- unmet need





### IGURE 2. PATIENTS SEEK EDUCATION VIA INTERNET SOURCES



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Patients experienced a range of emotions on their journey to receiving a diagnosis

• Patients perceived that their symptoms were dismissed by physicians who lacked sufficient understanding and knowledge of their condition

• Patients felt frustrated and mistrusted the healthcare system due to frequent

• Patients struggled with the loss of control over their body, which is a daily

• Treatment dose and frequency adjustments aimed at optimizing outcomes added to patients' mental and emotional burden

• Access to mental health services at the time of diagnosis was identified as an

Patients sought education about their disease from resources besides their neurologist

• Despite receiving education on the biology of their disease from their neurologist, patients conveyed that neurologists appeared to lack awareness of the presenting features of MMN and CIDP

• Patients also sought more understanding about the cause of their condition than what their neurologist provided

• This unmet need forced patients to obtain information about their disease from online sources or support groups (Figure 2)

Internet Sources	Patients use internet sources to stay informed about MMN or CIDP and to reinforce their neurologist's diagnosis. Websites used include: WebMD, MayoClinic, IG therapy manufacturer websites, and clinical trial websites			
Support Groups	All interviewed patients use support groups on Facebook (eg, MMN Warriors)			
oundations	Most patients are actively involved in foundations such as GBS/CIDP Foundation International			
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CIDP, chronic inflammatory demyelinating polyradiculoneuropathy; MMN, multifocal motor neuropathy; QoL, quality of life.

Patients required daily caregiver assistance and emotional support



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- All patients received immediate IG therapy either by intravenous infusion or a port
- Half of patients received IG therapy at home; others drove from 15 minutes to 2 hours to an infusion center
- Most patients (6/9 patients receiving intravenous IG therapy) received treatment on 2–3-week cycles
- All patients had IG dosing and frequency adjustments to determine how best to manage their symptoms
- Patient perception of not getting immediate symptom relief after IG treatment initiation could lead to a search for other treatment options
- Patients looked for clinical trials that may provide new treatment options
- Most patients (7/10) played an active role in their treatment decisions and advocated for themselves

Clearly, I want to be back where I was tomorrow or yesterday, but it is working in line with what the literature said it would... It's working more slowly than I want it to.

– Male patient with CIDP, age 60

Most patients (8/10) sought symptom relief outside of IG therapy

• Aside from their neurologist, patients sought support from other healthcare professionals to manage their symptoms (Figure 5)

FIGURE 5. HEALTHCARE PROFESSIONALS WHO HELP PATIENTS MANAGE THEIR SYMPTOMS



Neurologist

Neurologists are the primary contact for patients with MMN or CIDP. Most patients were still under the care of their diagnosing neurologist at time of interview

### Physical or occupational therapist, chiropractor, massage therapist Patients see a mix of healthcare professionals to help manage their symptoms. Additional avenues for symptom control included dietary adjustments and acupuncture

### Mental health professional

ome patients (5/10) seek support from mental health essionals on their own to manage depression and anxiety Other patients (2/10) report an unmet need for better and faste connections to mental health professionals after diagnosis









My group now consists of physical therapy, which is very difficult to find someone who understands MMN. I also work with a chiropractor that does applied kinesiology and energy work.

•••

### Advice interviewees would give to newly diagnosed patients with MMN or CIDP

- Advice from interviewees to newly diagnosed patients with MMN or CIDP included (Figure 6):
- "Be your own advocate!"
- "Have a strong support system!"

FIGURE 6. ADVICE FROM INTERVIEWEES TO NEWLY DIAGNOSED PATIENTS WITH MMN OR CIDP

> **Prepare for IG therapy** Still do the things you love Look after your mental health Move all the muscles you can move

Everyone's experiences are different

Have a strong support system

## **Be your own advocate**

Take small victories Consider a port **Don't give up on IG** Talk to other patients You're not going to die Be patient Stay hydrated for infusions

### CONCLUSIONS

for greater patient engagement

For patients with MMN or CIDP, the journey to an accurate diagnosis and appropriate treatment can profoundly impact their mental health and QoL

management and providing patients with educational material

during their visits may help improve communication and allow

Improved clinician education regarding disease symptom





Patient access to more effective treatments and optimization of current treatment modalities are also warranted



Although the small number of participants in this phase 1 qualitative study limits generalizability, the insights gained informed the development of a phase 2 quantitative survey with a larger patient population

### REFERENCES

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