

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^{1,2}
- 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 prognosis¹⁻³

OBJECTIVES

- To describe the the experiences of patients with 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 caring for those with MMN or 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 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

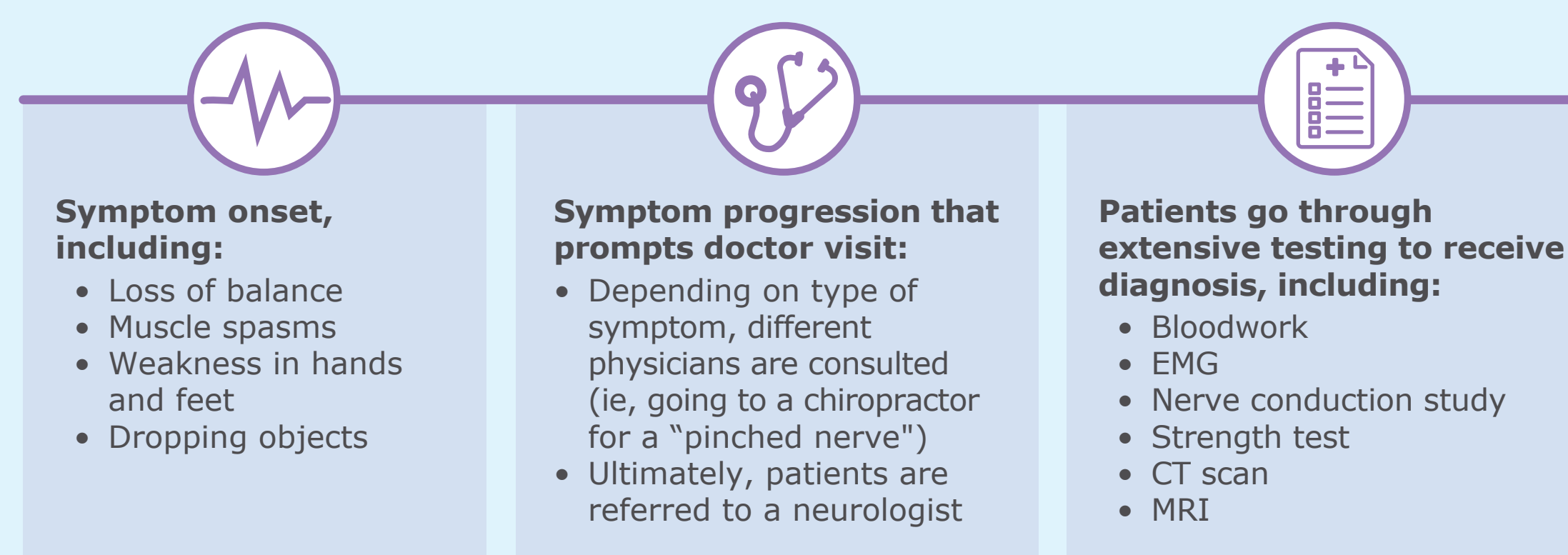
- Between March 21, 2023, and April 13, 2023, 10 patients (MMN = 6; CIDP = 4) were interviewed
 - Most were women (n = 7), aged 45–64 years (n = 6), living in the Northeastern United States (n = 4), with a postgraduate degree (n = 6), and access to commercial health insurance (n = 6)
- The following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

- 1 Patients experienced a range of emotions on their journey to receiving a diagnosis**
- 2 Patients sought education about their disease from resources besides their neurologists**
- 3 MMN and CIDP drastically affected patients' QoL and psychological health**
- 4 Patients desired additional treatment options**
- 5 Most patients (8/10) sought symptom relief outside of IG therapy**

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

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

FIGURE 1. PATIENT JOURNEY TO DIAGNOSIS INVOLVES VISITS WITH MULTIPLE PHYSICIANS



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

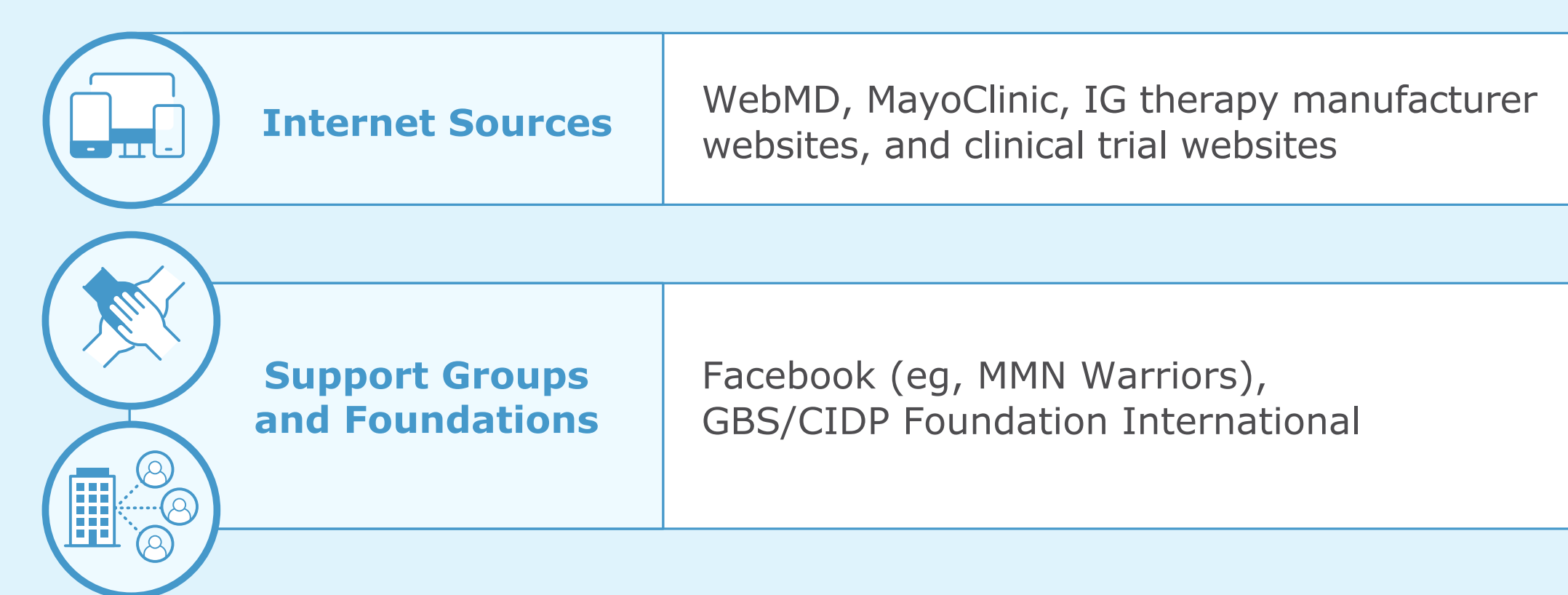
- Patients perceived that their symptoms were dismissed by physicians who lacked sufficient understanding and knowledge of their condition
- Patients struggled with the loss of control over their body, which is a daily reminder of their disease
- Treatment dose and frequency adjustments added to patients' mental and emotional burden

“ I kind of equate having this with a grieving process. You grieve the person that you used to be, and you have all the anger, the sadness, the depression, and then you come out the other side. But it's very frustrating. ”
– Female patient with MMN, age 60

2 Patients sought education about their disease from resources besides their neurologists

- Despite receiving education from their neurologists, patients conveyed that neurologists lacked awareness of the presenting features of MMN and CIDP
- Therefore, they sought more understanding about the cause of their condition from online sources or support groups (Figure 2)

FIGURE 2. PATIENTS SEEK EDUCATION VIA INTERNET SOURCES AND SUPPORT GROUPS



CIDP, chronic inflammatory demyelinating polyradiculoneuropathy; GBS, Guillain-Barré syndrome; IG, immunoglobulin; MMN, multifocal motor neuropathy.

“ There was nothing that they could give me to walk away with to read. ”
– Female patient with MMN, age 53

3 MMN and CIDP drastically affected patients' QoL and psychological health

- Patients living with MMN or CIDP experienced frustrations and challenges, which included unpredictable symptoms (Figure 3)

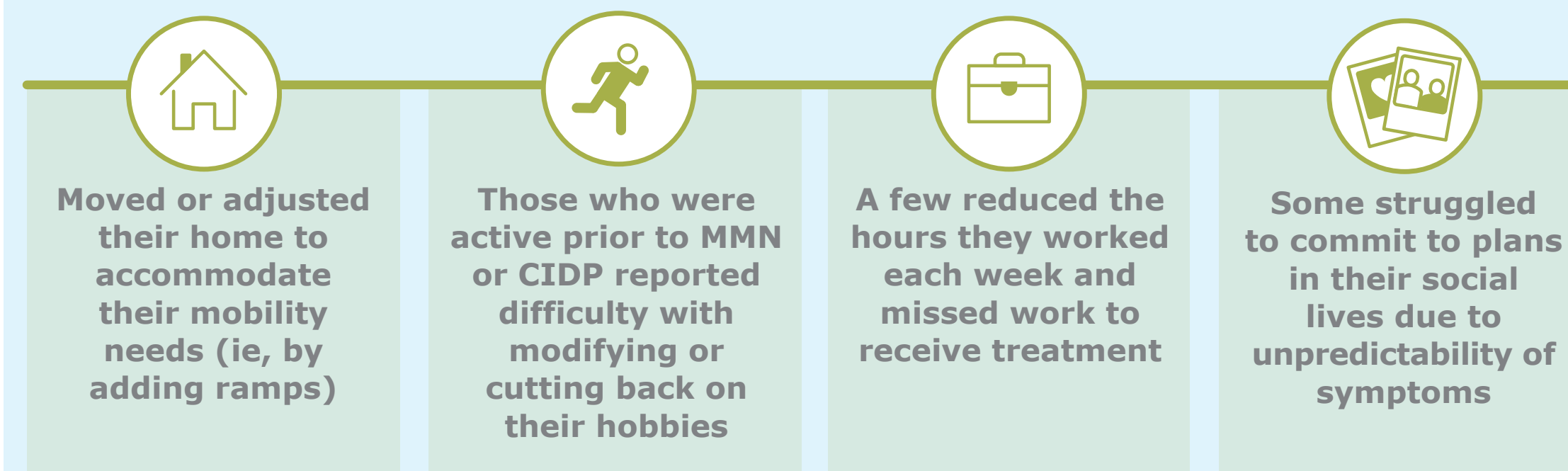
FIGURE 3. FRUSTRATIONS AND CHALLENGES OF LIVING WITH MMN OR CIDP

No cure Weakness Turns life upside down
Finding the right treatment Unpredictable symptoms
Can't do the things I used to enjoy
Communicating with physicians
Losing fine motor skills No control over body
Fatigue Declining mobility

CIDP, chronic inflammatory demyelinating polyradiculoneuropathy; MMN, multifocal motor neuropathy.

- Patients made adjustments to their homes, work schedules, hobbies, and social lives (Figure 4)

FIGURE 4. MMN AND CIDP IMPACT PATIENTS' QOL AND REQUIRE ADJUSTMENTS TO THEIR HOME, DAILY ACTIVITIES, WORK, AND SOCIAL LIFE



CIDP, chronic inflammatory demyelinating polyradiculoneuropathy; MMN, multifocal motor neuropathy; QoL, quality of life.

- Patients required daily caregiver assistance and emotional support

“ Frustrating things are opening a jar or something of that sort. It's humbling to need to ask someone for assistance to do the menial task that you never gave a second thought about prior. ”
– Male patient with CIDP, age 60

4 Patients desired additional treatment options

- All patients received immediate IG therapy either by intravenous infusion or a port
 - Half of the patients received IG therapy at home; others drove to an infusion center (15 minutes to 2 hours)
 - Most patients (6/9) received intravenous IG therapy on a 2–3 week cycle
 - 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, such as participating in clinical trials that may offer other therapies
- 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

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

- Besides neurologists, patients sought other healthcare professionals for management of their symptoms (Figure 5)

FIGURE 5. HEALTHCARE PROFESSIONALS WHO HELP PATIENTS MANAGE THEIR SYMPTOMS



CIDP, chronic inflammatory demyelinating polyradiculoneuropathy; MMN, multifocal motor neuropathy.

“ 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. ”
– Female patient with MMN, age 53

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

- Prepare for IG therapy** Still do the things you love
- Move all the muscles you can move** **Look after your mental health**
- Everyone's experiences are different** Have a strong support system
- Be your own advocate**
- Don't give up on IG** **Take small victories** **Consider a port**
- You're not going to die** **Be patient** **Talk to other patients**
- Stay hydrated for infusions**

CIDP, chronic inflammatory demyelinating polyradiculoneuropathy; IG, immunoglobulin; MMN, multifocal motor neuropathy.

CONCLUSIONS

- For patients with MMN or CIDP, the journey to an accurate diagnosis and appropriate treatment can profoundly impact their mental health and QoL
- Improved clinician education regarding disease symptom management and providing patients with educational material during their visits may help improve communication and allow for greater patient engagement
- 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

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This poster is intended for healthcare professionals



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DISCLOSURES

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