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 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.¹⁻³

OBJECTIVES

• To describe 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 their disease
  • Collect patient demographics

• Interviews were recorded and subsequently transcribed.

• Transcripts were reviewed to identify and code common themes relevant to the relative topics discussed.

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. Patients experienced symptoms and visited multiple physicians from less than a year to over a decade prior to receiving a diagnosis

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

  5. Patients struggled with the loss of control over their body, which is a daily reminder of their disease

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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.

REFERENCES


DISCLOSURES

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