

# A QUANTITATIVE STUDY ON THE PATIENT JOURNEY AND EXPERIENCE IN PATIENTS WITH CIDP AND MMN

Poster #192

Josh Feldman, BS<sup>1</sup>, Ade Ajibade, PhD<sup>2</sup>, Chafic Karam, MD<sup>3</sup>, Michelle Kirby, MSc, PMP<sup>2</sup>, Megan Gower, PharmD<sup>2</sup>, Chris Blair, MSc<sup>2</sup>, Faisal Riaz, MD<sup>2</sup>, Lauren Trumbull, MPH<sup>1</sup>, Brian Chen, MSc<sup>1</sup>, Jeffrey A Allen, MD<sup>4</sup>  
<sup>1</sup>Inspire, Arlington, VA, USA; <sup>2</sup>Takeda Pharmaceuticals USA, Inc., Lexington, MA, USA; <sup>3</sup>University of Pennsylvania, Philadelphia, PA, USA; <sup>4</sup>Department of Neurology, University of Minnesota, Minneapolis, MN, USA

Presenting author: Jeffrey A Allen

## INTRODUCTION

- Chronic inflammatory demyelinating polyradiculoneuropathy (CIDP) and multifocal motor neuropathy (MMN) are rare acquired, immune-mediated neuropathies<sup>1,2</sup>
- CIDP manifests as progressive, monophasic or relapsing-remitting, affecting the peripheral nerves and nerve roots<sup>3</sup>
- MMN is characterized by progressive, asymmetric weakness and muscle atrophy without sensory abnormalities<sup>2</sup>
- CIDP and MMN are life-altering conditions that are often difficult to diagnose and are associated with a substantial patient burden<sup>4</sup>
- This study aimed to understand the effect of MMN and CIDP on quality of life (QoL) and to evaluate patients' diagnostic and treatment journeys

## METHODS

### STUDY DESIGN

- This study was conducted through Inspire, an online community platform which enables members to share their disease experiences and treatment outcomes with other patients<sup>5</sup>
- A mixed-methods cross-sectional design was used
  - The quantitative study findings were developed from a 30-minute online cross-sectional survey that was tailored using qualitative patient insights
- Included patients (≥18 years old) must have resided in the US and have self-reported MMN or CIDP

### SURVEY VARIABLES AND ANALYSES

- The cross-sectional survey included a variety of questions on:
  - working ability and caregiver support
  - symptom onset, referrals and diagnosis
  - treatment
  - disease burden and QoL
- Results from the survey were quantitatively summarized

## RESULTS

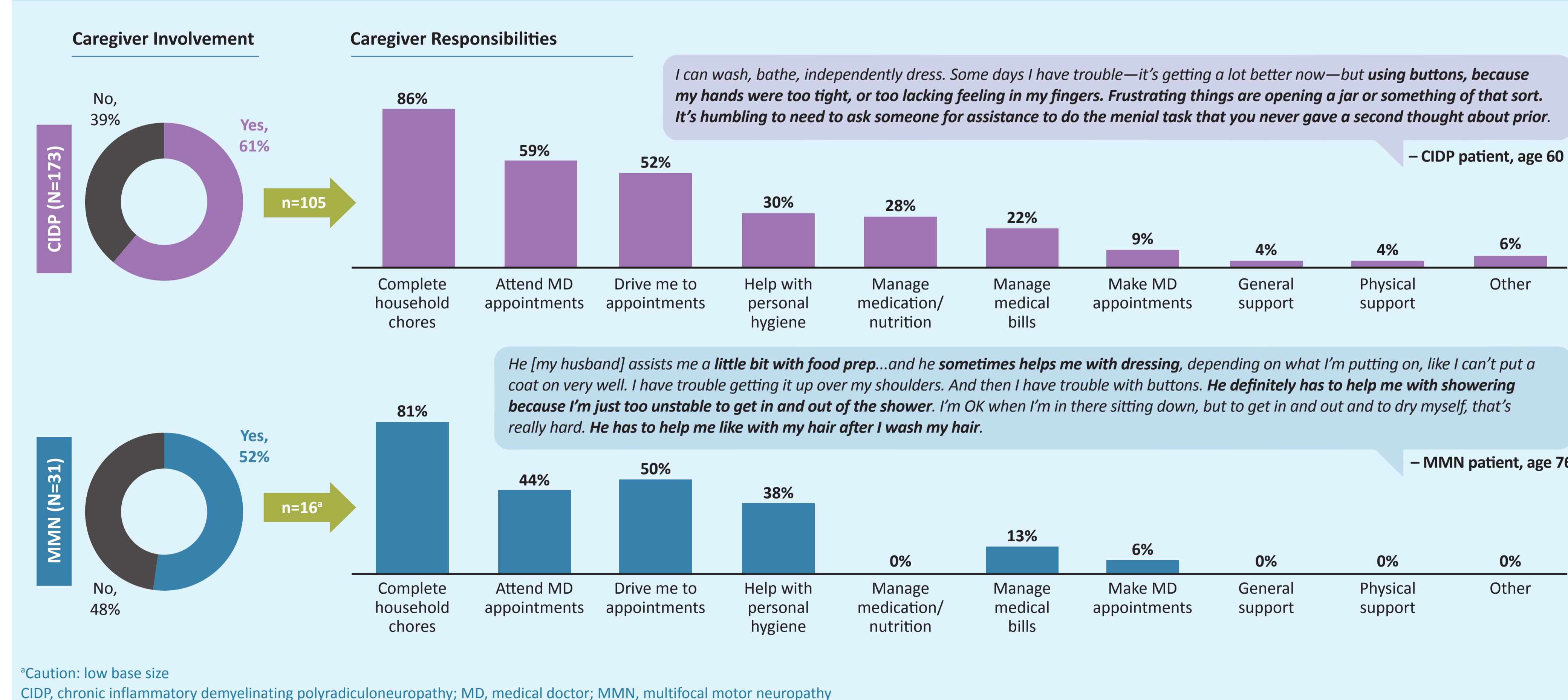
### STUDY POPULATION

- A total of 173 patients with CIDP and 31 patients with MMN were included
- There were similar proportions of men (49%) and women (51%) in the CIDP cohort
- More women (55%) reported MMN than men (45%)
- The mean age was 58.9 and 57.6 years in the CIDP and MMN groups, respectively
- Most patients identified as White/Caucasian (CIDP: 88%; MMN: 94%)
  - Followed by Black/African American patients in the CIDP group (7%) and Asian patients in the MMN group (13%)
  - Race/ethnicity was presented as a multi-select, generating results over 100%
- The survey was administered approximately 5 years following diagnosis, on average

### WORKING ABILITY AND CAREGIVER SUPPORT

- Approximately half of patients with MMN (48%) were considered full-time employees compared with 23% of patients with CIDP, who were more likely to be medically unable to work (CIDP: 28%; MMN: 13%)
  - Patients with CIDP or MMN frequently reported difficulties with performing lower-body strength activities and dexterous tasks, respectively
  - Many patients reported caregiver involvement (CIDP: 61%; MMN: 52%), generally with housework (CIDP: 86%; MMN: 81%) and attending medical appointments (CIDP: 59%; MMN: 44%) (Figure 1)

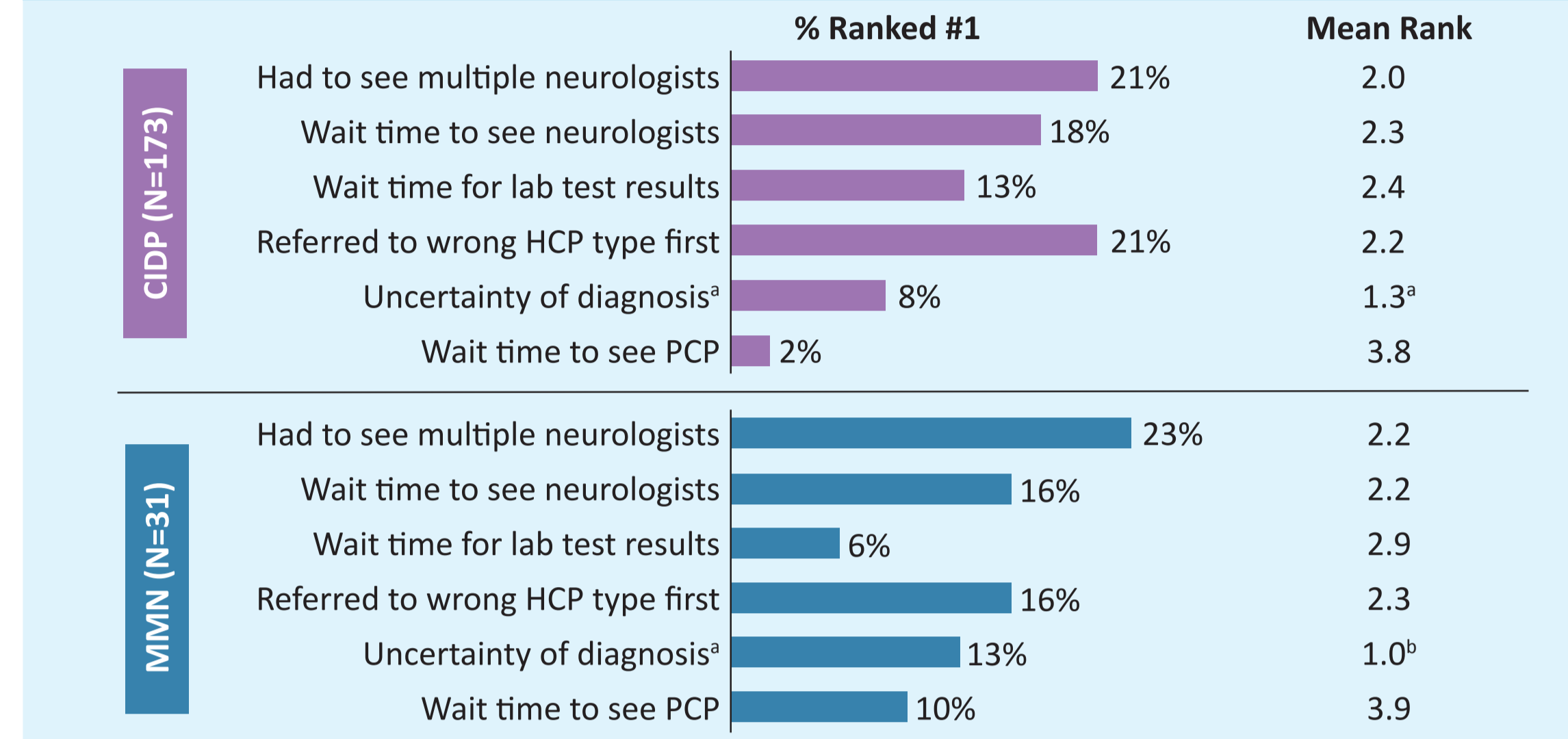
FIGURE 1: CAREGIVER INVOLVEMENT IN PATIENTS WITH CIDP AND MMN DAILY ACTIVITIES



## SYMPTOM ONSET, REFERRALS AND DIAGNOSIS

- Patients with CIDP indicated significantly more lower body symptoms (legs/feet) than patients with MMN (numbness/tingling, 87% vs 32%; weakness, 80% vs 58%; pain, 56% vs 16%, respectively; P < 0.05 for all)
  - All symptoms are patient-reported and therefore may not precisely align with expected clinical definitions of CIDP and MMN
- Many patients experienced symptoms >6 months before receiving a diagnosis (CIDP: 51% MMN: 90%); the delay was primarily caused by seeing multiple neurologists and long wait times for appointments (Figure 2)

FIGURE 2: PATIENT SELF-REPORTED REASONS FOR DIAGNOSTIC DELAY IN CIDP AND MMN

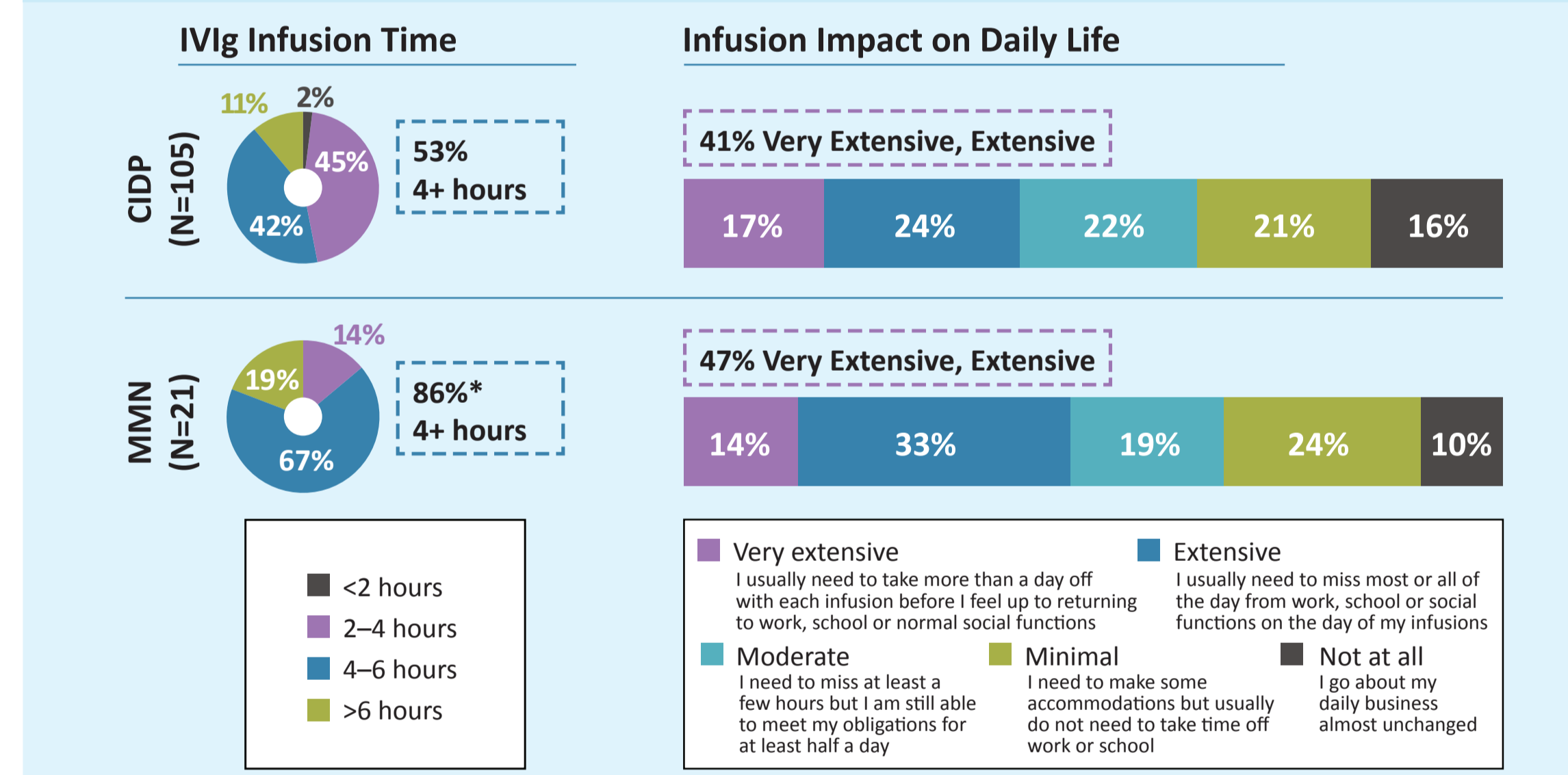


- Patients consulted with ≥3 healthcare providers (CIDP: 55%; MMN: 65%) and underwent several tests (mean: 5.2) including electromyography (EMG), nerve conduction study, antibody testing, MRI and spinal tap, before receiving a diagnosis
- Most patients specified neurologists as the diagnosing and/or treating physician (CIDP: 92%; MMN: 97%); approximately half were neuromuscular specialists (CIDP: 54%; MMN: 57%)
- Patients frequently consulted other specialists, most often a physical therapist (CIDP: 26%; MMN: 32%) to manage symptoms, although few sought mental health support (CIDP: 2%; MMN: 0%)

### TREATMENT

- Most patients received intravenous immunoglobulin therapy (IVIg) (CIDP: 75%; MMN: 74%); other treatments reported include subcutaneous immunoglobulin therapy (SCIg), oral and IV corticosteroids, azathioprine and rituximab; some patients (CIDP: 2%; MMN: 13%) reported not having received treatment
- More patients with MMN than patients with CIDP reported IVIg infusions of >4 hours; however, the impact of the infusion on daily life was relatively similar for both groups (Figure 3)

FIGURE 3: INTRAVENOUS IMMUNOGLOBULIN THERAPY TIME AND INFUSION IMPACT ON DAILY LIFE IN PATIENTS WITH CIDP AND MMN



- Dose adjustments, such as dose amount (CIDP: 43%; MMN: 60%) or frequency (CIDP: 57%; MMN: 64%), were common and may further hinder patients' ability to maintain treatment schedules

## DISEASE BURDEN AND QUALITY OF LIFE

- Patients requiring caregiver involvement reported greater disability, based on INCAT scores (Table 1)
- Men indicated significantly better Inflammatory Rasch-built Overall Disability Scale (I-RODS) disability scores than women (Table 1)
- Women indicated higher levels of anxiety and depression in the EQ-5D-5L (Table 1)

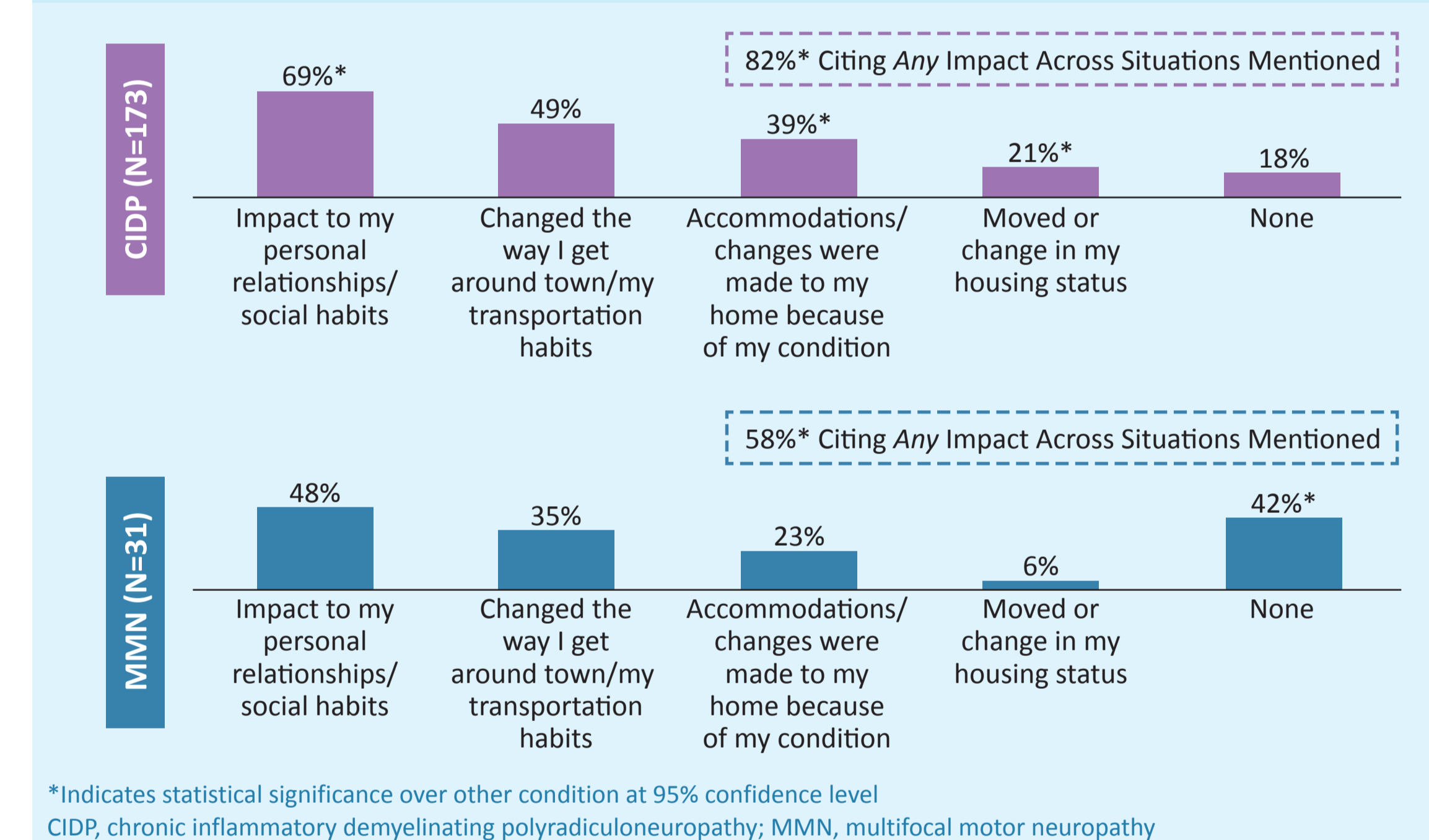
TABLE 1: MEAN QUALITY OF LIFE MEASURES BY GENDER AND CAREGIVER INVOLVEMENT IN PATIENTS WITH CIDP AND MMN

	Gender		Caregiver involvement	
	Male	Female	Caregiver	No Caregiver
INCAT <sup>®</sup> Arm (Lower score = better QoL)	1.57	1.79	1.93*	1.33
INCAT <sup>®</sup> Leg (Lower score = better QoL)	1.49	1.70	1.88*	1.19
INCAT <sup>®</sup> Total (Lower score = better QoL)	3.06	3.49	3.80*	2.52
I-RODS <sup>®</sup> (Higher score = better QoL)	35.05*	31.45	30.33	37.68*
MMN-RODS <sup>®</sup> (Higher score = better QoL)	40.43	38.12	37.75	40.67
EQ-5D-5L VAS <sup>®</sup> (Higher score = better QoL)	66.18	62.30	60.43	69.65*
EQ-5D-5L Anxiety/Depression <sup>d</sup> (Lower score = less anxiety/depression)	1.85	2.31*	2.28	1.81

\*Indicates statistical significance over other condition at 95% confidence level  
Scoring ranges: <sup>a</sup>0-10; <sup>b</sup>Raw RODS score 0-48, transformed to final score 0-100; <sup>c</sup>0-100; <sup>d</sup>1-5  
Note: CIDP and MMN are combined for all measures except I-RODS and MMN-RODS, which were asked exclusively to patients with CIDP and MMN, respectively  
CIDP, chronic inflammatory demyelinating polyradiculoneuropathy; EQ-5D-5L VAS, EuroQoL 5 Dimension 5 Level Visual Analog Scale; INCAT, Inflammatory Neuropathy Cause and Treatment; I-RODS, (Inflammatory) Rasch-built Overall Disability Scale; MMN, multifocal motor neuropathy; QoL, quality of life

- Patients with CIDP were significantly more likely than patients with MMN to indicate impact of their disease on their housing status, transportation habits or social life (Figure 4)

FIGURE 4: IMPACT OF DISEASE ACROSS HOUSING STATUS, TRANSPORTATION HABITS AND SOCIAL LIFE



## CONCLUSIONS

- Patients with CIDP and MMN experience burden related to diagnosis, treatment, symptoms and functional limitations
- Most patients with CIDP and MMN are debilitated to the extent that they require some level of caregiver support
- Patients often cycle through 3 or more healthcare providers and undergo multiple rounds of testing before arriving at a diagnosis
- Half of patients report seeing a neuromuscular specialist, with care being fragmented across different specialty providers
- This study, while limited by self-reported CIDP and MMN diagnoses, points to the need to broadly educate providers on these neuropathies as patients continue to seek information at various points of care; this can help optimize the patient experience and improve outcomes

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- Inspire | Health and wellness support groups and communities. <https://www.inspire.com/>

For a digital version of this poster, please scan here or visit <https://tiny.one/3sD1519pF4>

This poster is intended for healthcare professionals



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## DISCLOSURES

BC, JF, and LT are employees of Inspire. AA, MK, MG, CB, and FR are employees of Takeda Pharmaceuticals USA, Inc., and are Takeda shareholders. CK has received honoraria for consulting for Takeda, Argenc, AstraZeneca, Sanofi, UCB, Alexion, Ionis, Neuroderm, Corino, and Alnylam. He has received research funding from Ionis and AstraZeneca. JA is a consultant for Argenc, Alnylam, Alexion, Annexon, CSL Behring, Grifols, Takeda, Immunovant, Immunopharma, and Pfizer.

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