

Impact of CIDP on Daily Activity and Participation: I-RODS Analysis from a US Patient Survey

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Introduction

- Chronic inflammatory demyelinating polyneuropathy (CIDP) is a rare peripheral neuropathy with an estimated prevalence of 1–9 cases per 100,000 individuals and an annual incidence of 0.5–1.6 per 100,000¹
- The most common symptoms are difficulty walking and using arms and legs, muscle weakness and altered sensation (e.g., numbness and tingling)²

IMPACT IN REAL-WORLD SETTING

- Although treatable, following remission, CIDP is often associated with relapses during or after treatment, which can lead to permanent disability
- The impact on daily functional activity and participation in a real-world setting has previously gone undocumented

US PATIENT SURVEY

- Here, we employed a US nationwide survey of CIDP patients to assess the impact of disease-related disability to perform daily activities and assess the extent and effects of diagnostic delay

Aim

- To assess the impact of CIDP on disease-related daily activities and participation, and physical function

Methods

- Approximately 3250 individuals aged ≥18 years, recruited by the GBS|CIDP Foundation and self-reported to have CIDP, were invited to complete an online survey; of these, 475 completed the survey and their responses were used to assess daily activity and participation
- Patient diagnosis and treatment patterns were evaluated; impact on daily activity and participation was measured using the patient-reported Inflammatory Rasch-built Overall Disability Scale (I-RODS), and physical function was measured using the Patient Reported Outcomes Measurement Information System Physical Function T-score (PROMIS PF T-score)
- Data were analyzed overall and by stratification of patients based on the likelihood of an accurate CIDP diagnosis, defined as shown in **Table 1**

Table 1: Stratification of patients based on likelihood of accurate CIDP diagnosis

Unlikely CIDP patient

- Reported no muscle weakness as symptom of CIDP
- Did not report having neurophysiologic tests performed when diagnosed

Somewhat likely CIDP patient

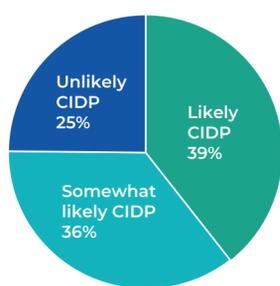
- Reported weakness, but not consistently
- Reported symptoms were at their worst in less than 2 months (without prior diagnosis of Guillain-Barré syndrome [GBS])
- Reported symptoms were not symmetric

Likely CIDP patient

- Absence of the above-listed factors
- Includes patients whose symptoms reached their worst in less than 2 months with a previous diagnosis of GBS

- There were 187, 170 and 118 patients with likely, somewhat likely and unlikely CIDP, respectively (**Figure 1**)

Figure 1: Percentage of respondents classified as either likely, somewhat likely or unlikely CIDP patients



Patients were classified according to the criteria listed in Table 1.

Conclusion

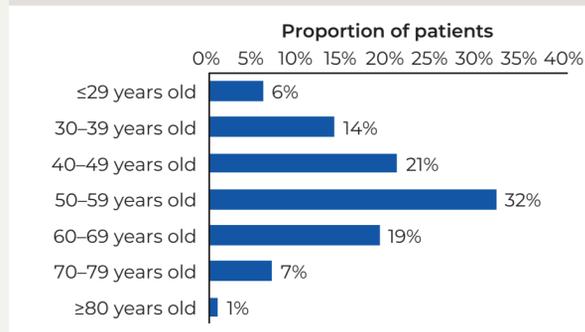
- Findings from this nationwide US survey demonstrate that CIDP significantly impacts daily activity and participation, including the simplest daily activities
- Diagnosis of CIDP is delayed in a large number of patients

Results

AGE AT CIDP DIAGNOSIS AND CURRENT TREATMENT

- The age distribution is shown in **Figure 2**; mean age at time of CIDP diagnosis was 51 years
- Common current treatments were intravenous immunoglobulin (63%), corticosteroids (19%) or immunosuppressive medicines (16%)

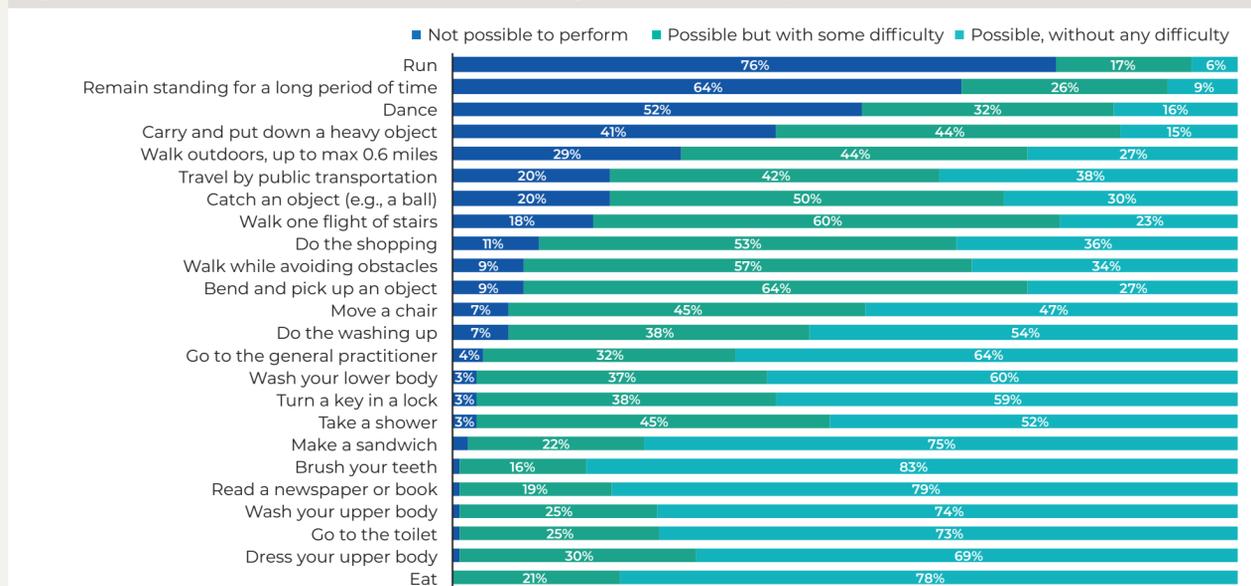
Figure 2: Age at the time of CIDP diagnosis



I-RODS: DIFFICULTY WITH PERFORMING DAILY ACTIVITIES

- A substantial subpopulation reported being unable to, or only with difficulty, perform the easiest items: going to the toilet (27%), eating (22%), reading a newspaper or book (21%) and brushing teeth (17%) (**Figure 4**)
- The majority of patients reported being unable to, or only with difficulty, perform activities at the middle-to-high difficulty level: walking outdoors (73%), walking one flight of stairs (77%) and running (94%) (**Figure 4**)

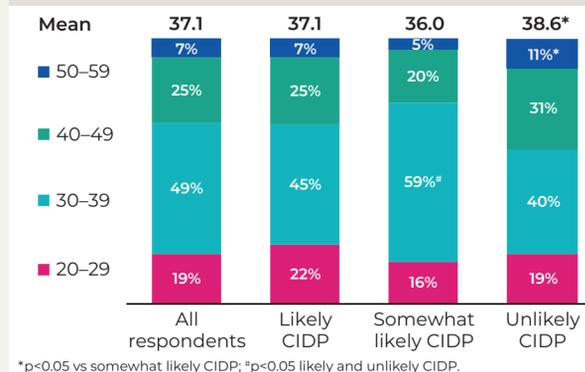
Figure 4: I-RODS: Proportion of patients experiencing difficulty with daily activities



PROMIS PHYSICAL FUNCTION T-SCORE: IMPACT OF LIKELIHOOD OF DIAGNOSIS

- Overall, 68% (49%+19%) of patients were more than one standard deviation [>10 points] below the US norm T-score of 50 (**Figure 5**)
- Across strata, these percentages were 67% and 76% for those with likely or somewhat likely CIDP but 58% for “unlikely CIDP”
- Those with “unlikely CIDP” were least likely to be substantially impaired on physical function (T-score <40 ; $p<0.05$ vs “somewhat unlikely CIDP”)

Figure 5: Impact of likelihood of CIDP diagnosis on PROMIS PF T-score

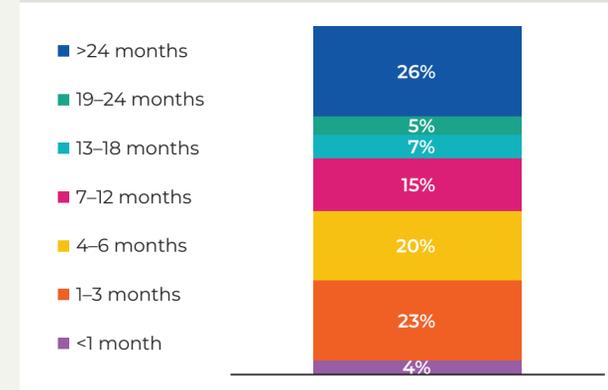


* $p<0.05$ vs somewhat likely CIDP; * $p<0.05$ likely and unlikely CIDP.

TIME BETWEEN FIRST SYMPTOMS AND DIAGNOSIS

- There was a median of 7 months between patients noticing the first symptoms and receiving their CIDP diagnosis (**Figure 3**)
- For 26%, the time was more than 24 months

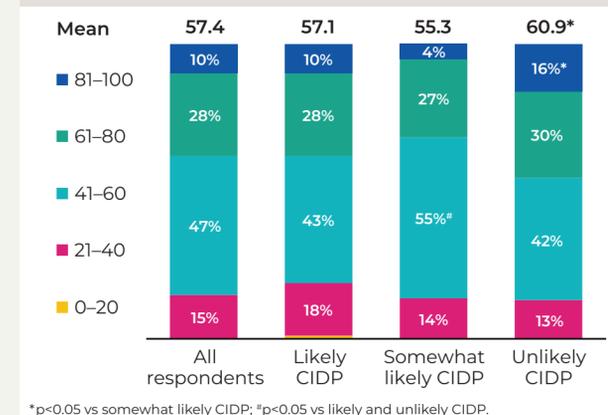
Figure 3: Time between noticing first symptoms and CIDP diagnosis



I-RODS: IMPACT OF LIKELIHOOD OF CIDP DIAGNOSIS

- Patients who were unlikely to have received an accurate CIDP diagnosis were most likely to have the best range of I-RODS centile scores (81–100) (**Figure 6**)

Figure 6: Impact of likelihood of CIDP diagnosis on I-RODS centile score



* $p<0.05$ vs somewhat likely CIDP; * $p<0.05$ vs likely and unlikely CIDP.

References

- Dalakas MC. *Nat Rev Neurol*. 2011; **7**:507–517.
- Mathey EK, et al. *J Neurol Neurosurg Psychiatry*. 2015; **86**:973–985.

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