

Lived Experiences of Chronic Inflammatory Demyelinating Polyneuropathy: Global Patient and Caregiver Perspectives

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Background

Chronic inflammatory demyelinating polyneuropathy (CIDP; also known as chronic inflammatory demyelinating polyradiculoneuropathy) is a rare, neurological autoantibody condition where the immune system destroys the protective myelin sheath around peripheral nerves; this causes progressive, debilitating motor and sensory symptoms, such as muscle weakness, numbness, and fatigue, which severely impact patients’ quality of life¹

Treatment recommendations primarily rely on intravenous immunoglobulin (IVIG) or subcutaneous immunoglobulin (SCIG), corticosteroids, plasma exchange, and immunosuppressants¹

- Delivery of these treatments is often time-consuming and carries side effects¹

CIDP is associated with significant disability, symptom and treatment burden, and impaired health-related quality of life; however, data on patient and caregiver perspectives are lacking^{1–3}

Objective

This study aimed to characterize the lived experiences of patients and caregivers throughout the CIDP journey

Methods

- Qualitative, virtual, individual interviews and group sessions with patients and caregivers living in Australia, China, Germany, Italy, Japan, and the United States (US) were conducted in April to June 2021
- Eligible patients were aged >18 years and currently receiving chronic treatment
 - Eligible caregivers represented a patient meeting the above criteria
- Participants were recruited via the GBS/CIDP Foundation International and Adept Field Solutions using purposive sampling
- Interviews and group sessions were conducted in native languages with live English translation
- Transcripts were analyzed using inductive and deductive thematic analysis to identify insights according to four *a priori* themes

of diagnosis, impact on daily life, clinical care and healthcare provider (HCP) relationships, and treatment experiences

- The regional insights presented for each theme reflect shared subthemes that are common to both countries grouped within a region (i.e., Australia/the US, Germany/Italy, and China/Japan) and that are distinct from the global insights and those of other regions

Results

Participant Characteristics

- In total, 19 participants were included from the US (7 patients; 2 caregivers), Germany (3 patients), Italy (2 patients), China (2 patients), Japan (2 patients), and Australia (1 patient)
 - Most of the 17 patient participants were White (12 [71%]), female (11 [65%]), aged ≥50 years (12 [71%]) and diagnosed ≤8 years prior (11 [65%]) (Table 1)
 - Both caregiver participants were spouses of US patient participants

Qualitative Patient and Caregiver Lived Experience Insights

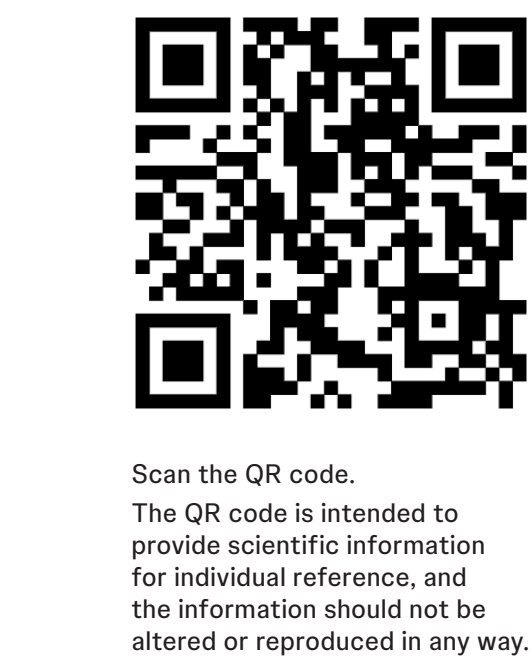
- Each of the four global themes of qualitative participant insights (Figure 1) also had related regional insights (Table 2)

Table 1. Patient participant demographic characteristics ^a	
Characteristic	Patient Participants (n=17)
Age bracket at the time of study, years	
30–39	1 (6)
40–49	4 (24)
50–59	4 (24)
60–69	7 (41)
70+	1 (6)
Gender	
Male	6 (35)
Female	11 (65)
Race/Ethnicity	
White	12 (71)
Chinese	2 (12)
Japanese	2 (12)
African American	1 (6)
Country of residence	
United States	7 (41)
Germany	3 (18)
China	2 (12)
Italy	2 (12)
Japan	2 (12)
Australia	1 (6)
Time since diagnosis, years	
1–4	4 (24)
5–8	7 (41)
9–12	1 (6)
13–16	3 (18)
17–20	2 (12)

Data are n (%). ^aPatient characteristics were self-reported and exclude the two caregivers.

Table 2. Theme descriptions and regional insights				
Theme	Description	Regional Insights		
		Australia and US	Germany and Italy	China and Japan
Diagnosis	Diagnosis was often delayed because of misdiagnoses, the need for multiple HCP visits, and limited HCP awareness of CIDP	Participants felt dismissed and minimized	Participants wanted to understand underlying causes and pathology	Participants sought second opinions from different specialists and hospitals
Impact on daily life	Living with CIDP presented major challenges and physical limitations related to mobility, fatigue, and motor skills, which impacted quality of life and required lifestyle changes	Participants discussed the toll of fatigue, brain fog, and living with a progressive disease	Participants reported loss of employment and hobbies	Participants spoke about impacts on cultural practices and education
Clinical care and HCP relationships	Participants were often satisfied with their care experiences, but poor communication and feeling dismissed challenged their relationships with HCPs	Participants reported a need for substantial travel to access knowledgeable specialists	Participants said that COVID-19 pandemic disruptions reduced in-person care	Participants described the high volume of clinic visits
Treatment experiences	Most patients received IVIG or SCIG but desired treatments with shorter infusion times, less frequent administration, and local access compared to IVIG and SCIG	Participants reported a high burden of infusion delivery and frequent needle insertion	Participants stated that SCIG regimens offered more consistency and flexibility than IVIG regimens	Participants desired future treatments with fewer side effects

CIDP=chronic inflammatory demyelinating polyneuropathy, HCP=healthcare provider, IVIG=intravenous immunoglobulin, SCIG=subcutaneous immunoglobulin, US=United States.



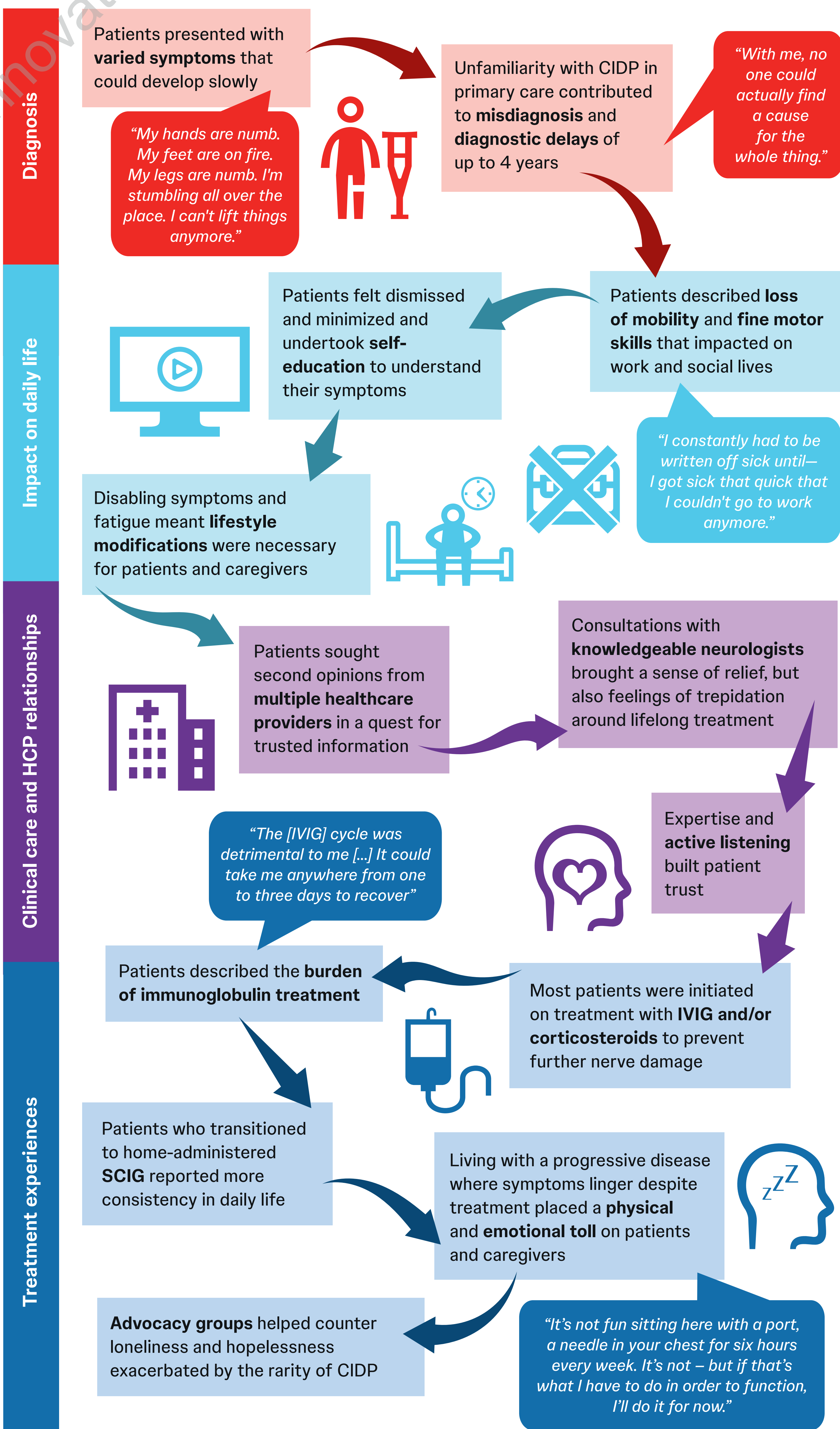
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Key Takeaways

- ✓ Patient- and caregiver-lived experience themes were identified across diagnosis, impact on daily life, clinical care and HCP relationships, and treatment experiences
- ✓ Patients with CIDP experience challenges and impacts to quality of life, such as diagnostic delays, reduced mobility and fine motor skills, and burdensome treatment regimens that limit freedom and convenience
- ✓ Greater HCP awareness of challenges beyond the clinic can improve support for patients and caregivers throughout the CIDP journey

Figure 1. Key global insights from the CIDP journey



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