# Refining a conceptual model of patient experiences in chronic inflammatory demyelinating polyneuropathy: Integrating new patient perspectives

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## Introduction

- Chronic inflammatory demyelinating polyneuropathy (CIDP) is a rare, autoimmune disorder of the peripheral nervous system[1-3]
- CIDP is characterized by progressive muscle weakness and impaired sensory function[4]
- Standard of care options for patients with CIDP include intravenous immunoglobulin (IVIg; typically at an administration center every 3-4 weeks over approximately 3 hours), subcutaneous immunoglobulin (SCIg; typically self-administered at home 1-3 times per week) and/or corticosteroid treatment (typically oral administration with regimens varying by patient)[5-7]
- Many of the existing treatment options have limitations in terms of safety and tolerability, including assorted short- and long-term side effects[7, 8] and administration interfering with patients' daily, social, leisure and work activities[9]
- Understanding the experience of CIDP and treatment preferences directly from patients can inform patient-focused drug development, and development of novel therapies [10, 11]
- A conceptual model that visually represents the patient experience of a disease can be used to communicate the specific health experiences/concepts that are important for novel therapies to address [12]

## Objective

- This study aimed to understand key CIDP patient experiences to inform patient-focused drug development (PFDD)

## Methods

- A preliminary conceptual model was iteratively developed based on a targeted literature review (TLR) and an initial round of 45 minute, web-assisted concept elicitation interviews [13]
- Refinements to enhance the model's comprehensiveness were based on a second round of web-assisted interviews, which included 60 minutes of concept elicitation
  - The second round of interviews included additional questions to explore select symptoms and impacts and aspects of treatment experience
- Adult patients from the United States with a confirmed CIDP diagnosis (as verified via patient portal screenshots, medical paperwork, prescription photographs, and/or clinician-completed forms) who were receiving IVIg, SCIg, corticosteroids or were treatment naïve were recruited by a specialist patient recruitment agency
- Interview recordings were transcribed verbatim and analyzed in ATLAS.ti qualitative analysis software using content analysis for concept elicitation (CACE) [14, 15]

## Results

- Twenty-eight interviews were conducted across two rounds, see **Table 1** for demographic and **Table 2** health characteristics
- Participants reported many symptoms of CIDP, most frequently: muscle weakness (n=27), numbness (n=26), fatigue (n=23), loss of balance (n=23), tingling/pins and needles (n=19) and nerve pain (n=15)
- CIDP symptoms negatively impacted participants' daily lives (n=28; primarily mobility, activities of daily living, fine motor skills, sleep), emotions (n=27; including depression/sadness, fear/anxiety/worry), hobbies/leisure (n=26; primarily exercise/physical activity), relationships/social life (n=22), ability to live without adaptations/support (n=19) and work (n=18)
- Many of the reported advantages and disadvantages of IVIg, SCIg and corticosteroids were specific to the attributes of each treatment, however, most participants considered their treatments successful because symptom control (predominantly muscle weakness) resulted in improved health-related quality of life
- Better efficacy, fewer side effects and reduced administration burden were identified as unmet treatment needs by patients
- These findings were used to finalize a conceptual model of the patient experience of CIDP (**Figure 1**)
- Key updates made to the interim conceptual model[13] included adding, re-naming or dividing concepts to better represent the patient-related findings (e.g. clarifying that numbness, tingling/pins & needles and nerve pain were distinct sensory symptoms); using bold text to indicate which concepts were reported in n≥14 interviews; separating general, medical center and home setting IVIg advantages and disadvantages

**Table 1. Demographic characteristics (self-reported)**

| Characteristic | Statistic (N=28) |
|---|---|
| **Years of age, mean (SD); median [Range]** | 55.4 (17.3); 58.5 [23–84] |
| **Sex, n (%)** | |
| Male | 14 (50%) |
| Female | 14 (50%) |
| **Race/ethnicity[†], n (%)** | |
| White | 18 (64%) |
| Black or African American | 6 (21%) |
| Hispanic/Latino and White | 2 (7%) |
| Asian | 2 (7%) |
| **Highest level of education completed, n (%)** | |
| College 4 years or more (College graduate) | 9 (32%) |
| Advanced or graduate/postgraduate degree | 9 (32%) |
| College 1 to 3 years (Some college or technical school) | 6 (21%) |
| High school diploma or equivalent (Grade 12 or GED) | 3 (11%) |
| Other: Nursing qualification | 1 (4%) |
| **Current employment status, n (%)** | |
| Working part time in paid job | 7 (25%) |
| Retired | 6 (21%) |
| Working full time in paid job | 5 (18%) |
| Not working due to CIDP | 5 (18%) |
| Not working due to medical problems other than CIDP | 2 (7%) |
| Full-time homemaker | 1 (4%) |
| Student | 1 (4%) |
| Other: Self-employed | 1 (4%) |

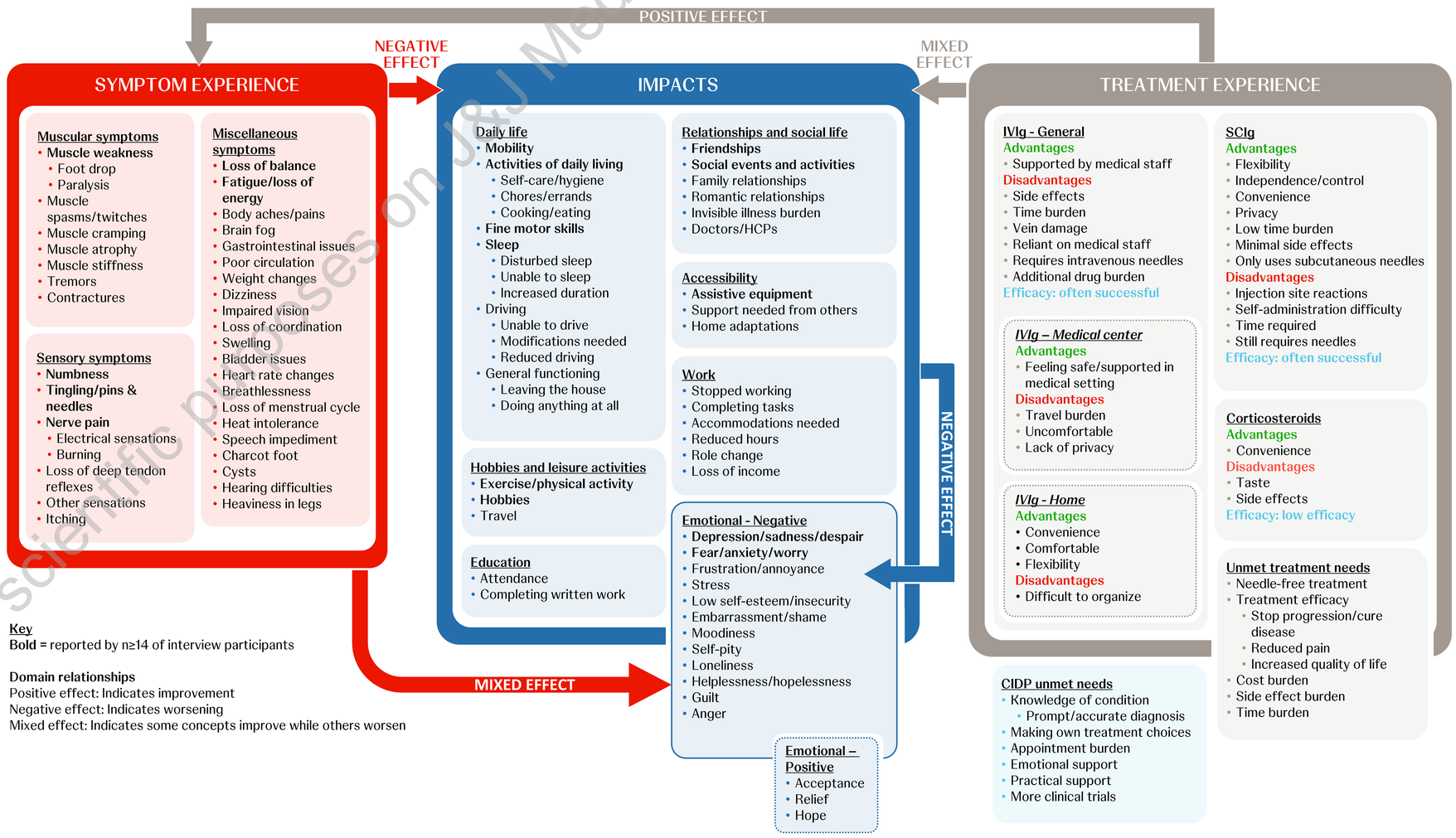
[†] Not mutually exclusive, participants could select more than one category

**Table 2. Clinical characteristics (self-reported)**

| Characteristic | Statistic (N=28) |
|---|---|
| **Years since diagnosis, mean (SD); median [range]** | 6.4 (5.4); 5.1 [0.0–24.0] |
| **Current treatments[†], n (%)** | |
| IVIg, medical center | 13 (76%) |
| IVIg, home | 4 (24%) |
| SCIg, home | 10 (36%) |
| Corticosteroids | 3 (11%) |
| **Rating of current health status, n (%)** | |
| Excellent | 0 (0%) |
| Very good | 4 (14%) |
| Good | 13 (46%) |
| Fair | 8 (29%) |
| Poor | 3 (11%) |
| **Primary type of medical insurance[†], n (%)** | |
| Medicare | 14 (50%) |
| Health insurance - employer | 8 (29%) |
| Health insurance – individual market | 4 (14%) |
| Medicaid | 3 (11%) |
| Uninsured | 1 (4%) |
| Other | |
| COBRA Plan | 1 (4%) |
| Tricare For Life | 1 (4%) |
| Unspecified insurance type | 1 (4%) |

[†] Not mutually exclusive, participants could select more than one category

**Figure 1: Conceptual model of the patient experience of CIDP**




## SUMMARY/CONCLUSION

- The final conceptual model of the patient experience of CIDP can inform PFDD by depicting the symptoms that patients consider most important to treat, the impacts of these symptoms and perspectives on current treatment attributes
- Muscle weakness continues to be a particularly debilitating symptom of CIDP that impacts functioning across numerous aspects of patients' lives
- For patients with CIDP, novel therapies that lessen treatment burden and side effects while targeting key symptoms are essential
- By clarifying the symptoms that matter most and patient-reported disadvantages of current treatments, this model underscores the urgent need for therapies that meaningfully improve daily functioning and align with patient priorities
- These insights should guide innovation in CIDP to ensure future therapies deliver on outcomes that matter to patients



**References**

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## Disclosures

KS, AB, JW, LF and SP are employees and stockholders of Johnson & Johnson. JM, HE and SK are employees and stockholders of Clarivate. EC is an employee of Clarivate. Clarivate was sponsored by Johnson & Johnson to conduct this study and dissemination.

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