

# Employment, daily activities and caregiver burden in CIDP: results of a real-world US survey

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## Background

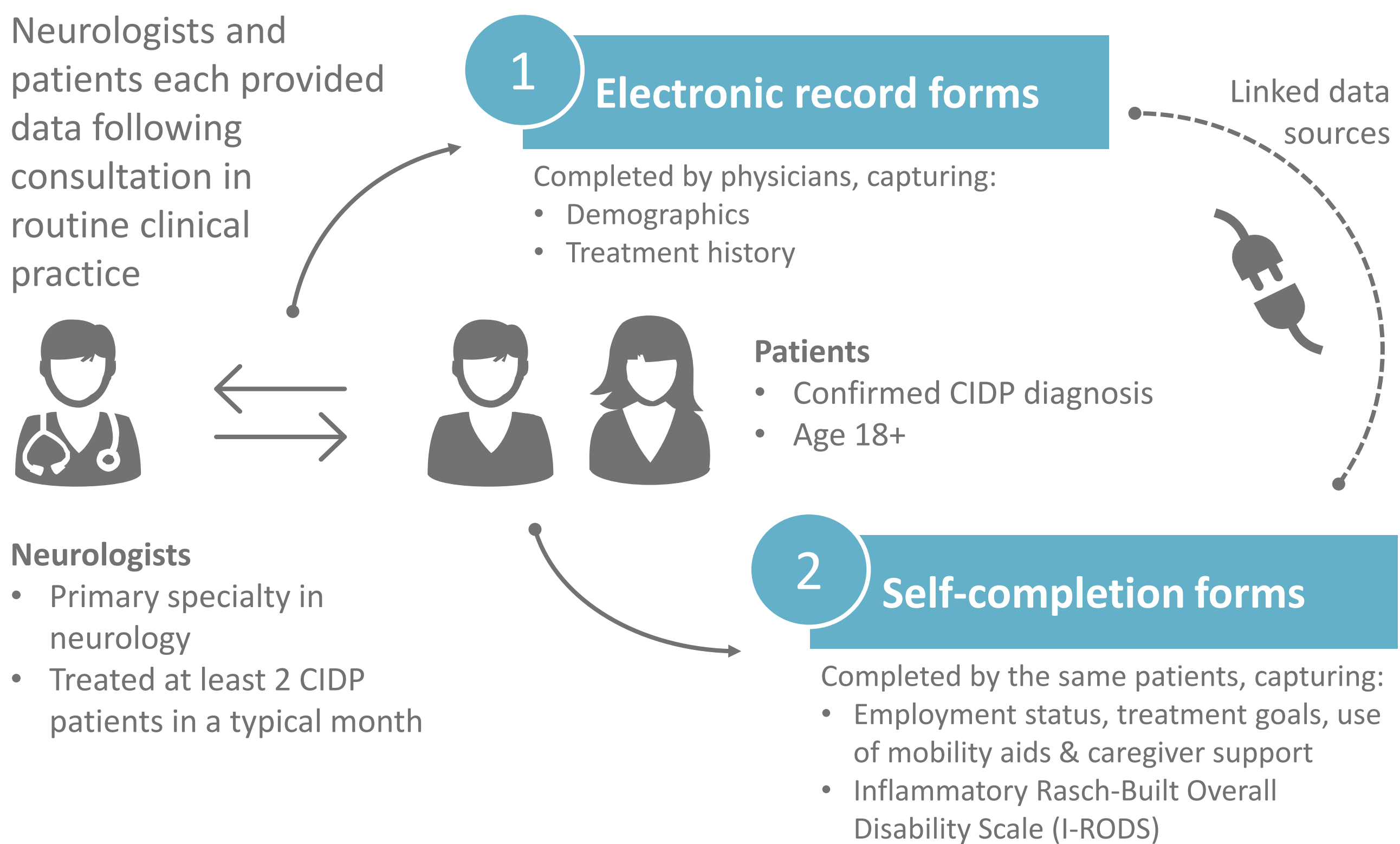
- Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) is a rare, progressive immune-mediated neurological disorder that causes disability due to limb weakness and/or sensory deficits.
- Real-world evidence reported by patients and their physicians is valuable for assessing the needs and burden associated with CIDP.

## Objectives

To characterize the burden experienced by patients with CIDP in the United States (US).

## Methods

- This was a secondary analysis of data collected as a part of Adelphi's **CIDP Disease Specific Programme**<sup>TM</sup>, a real-world cross-sectional survey including US CIDP patients and their neurologists conducted between September 2022-April 2023.
- Only matched data, consisting of physician- and patient-reported data, were utilized in these analyses. In total, 76 US patients were included. Sample sizes vary per question as their completion by patients was voluntary.



## Results

### 1. Demographics, treatment goals and symptom severity

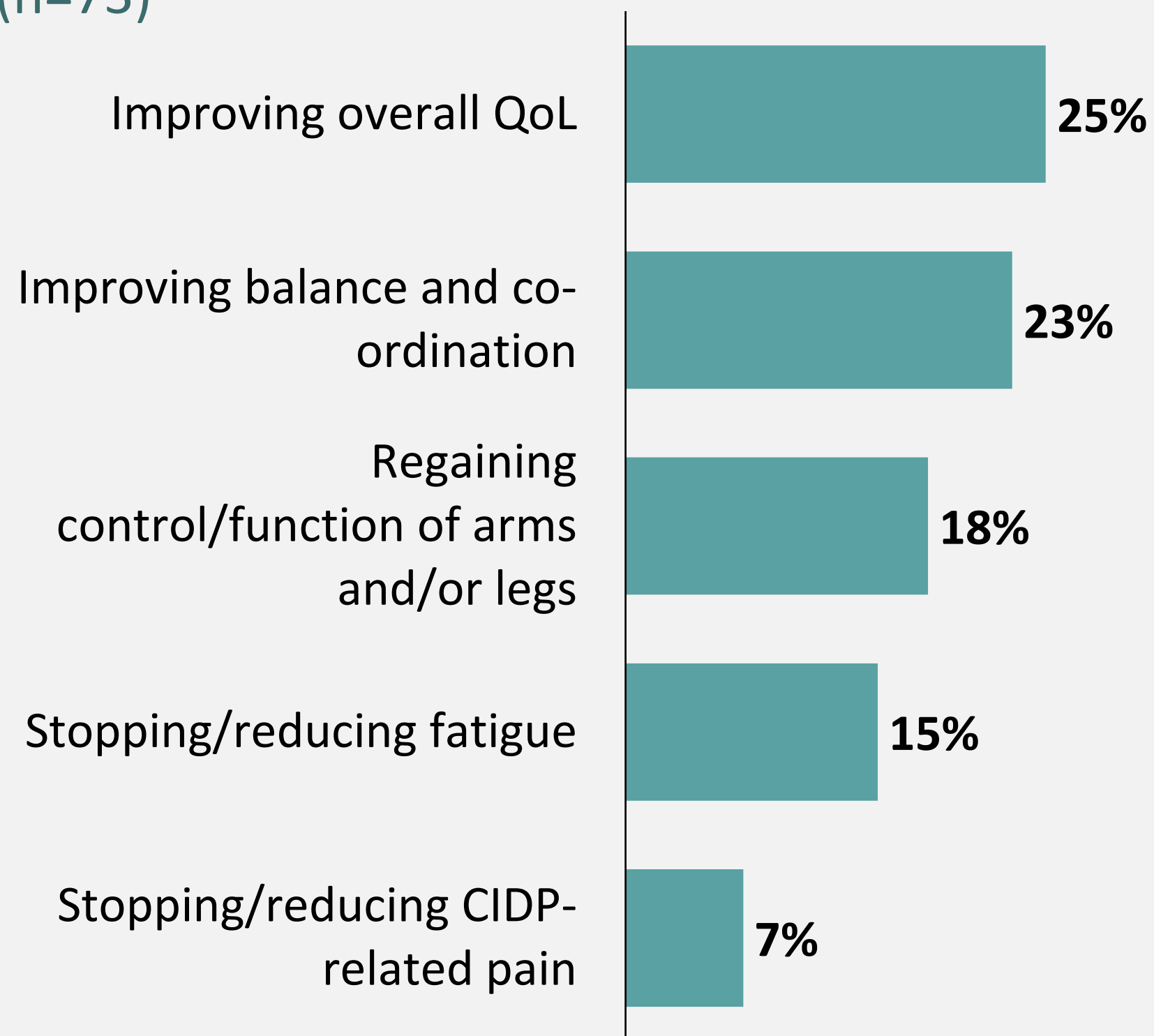
- Mean (SD) patient age was 57.5 (10.5) years, and 64% were male. The majority of patients were receiving immunoglobulins at time of survey (**Table 1**).
- "Improving overall quality of life" was most often reported by patients as their most important treatment goal (**Figure 1**).
- Despite treatment (n=62), 42% of patients reported they continued to experience moderate-severe symptoms.

Table 1. Patient characteristics

	N=76
Age (years), mean (SD)	57.5 (10.5)
Sex, male, N (%)	49 (64%)
Receiving treatment, N (%)	62 (82%)
Immunoglobulins	39 (63%)
Corticosteroids	24 (39%)
Other*	15 (24%)

\*Non-steroidal immunosuppressants: 8 (13%); biologics: 3 (5%); neuropathic pain therapies: 3 (5%); plasmapheresis: 1 (2%)

Figure 1. Most important treatment goals (top 5) (n=73)



### 2. Caregiver burden and utilization of mobility aids

- Over a quarter of patients required caregiver help, usually from a partner/spouse (**Figure 2**).
- Mobility aids were utilized by 59% of patients, with a cane/walking stick being the most common (**Figure 3**).

Figure 2. Caregiver burden

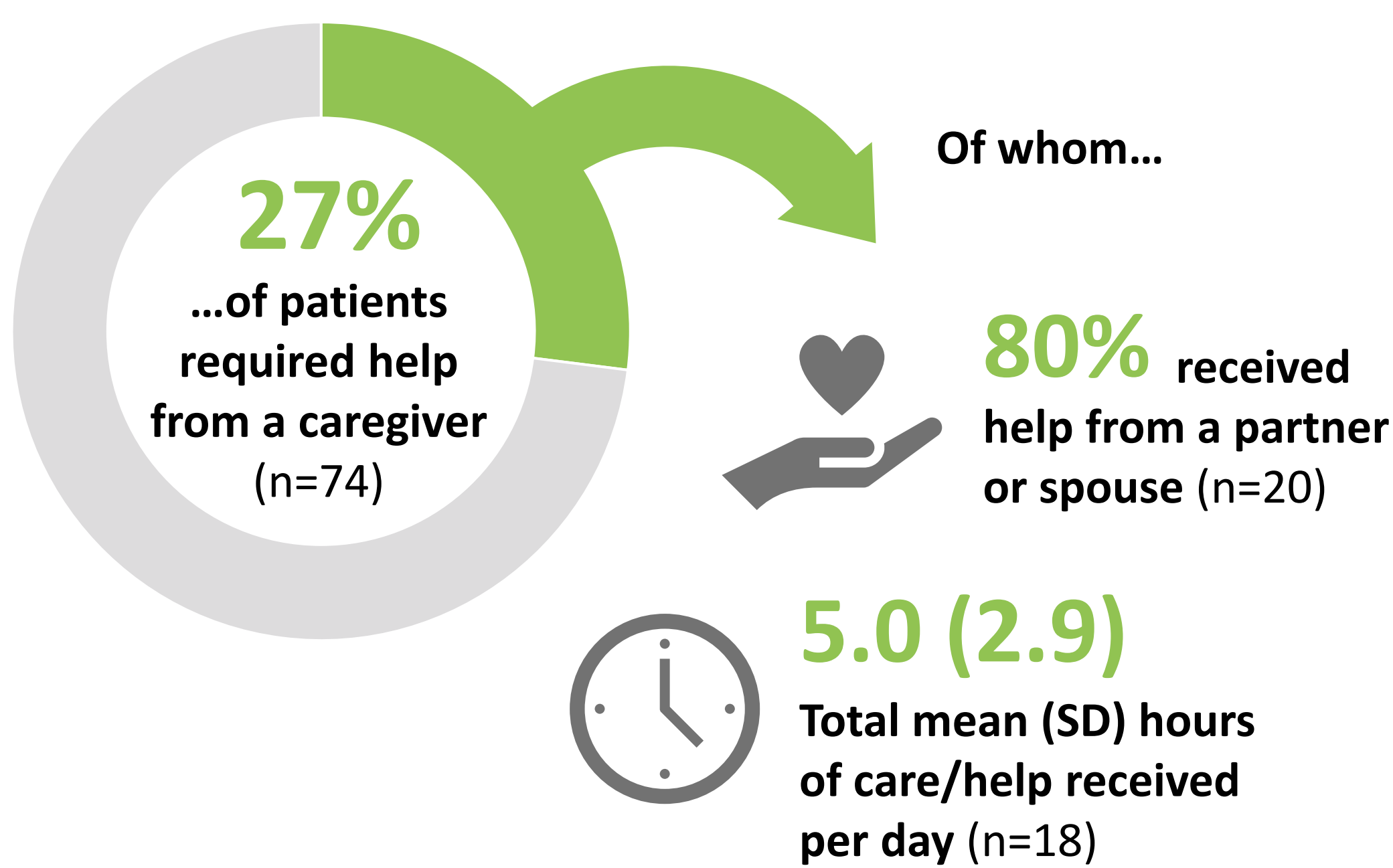
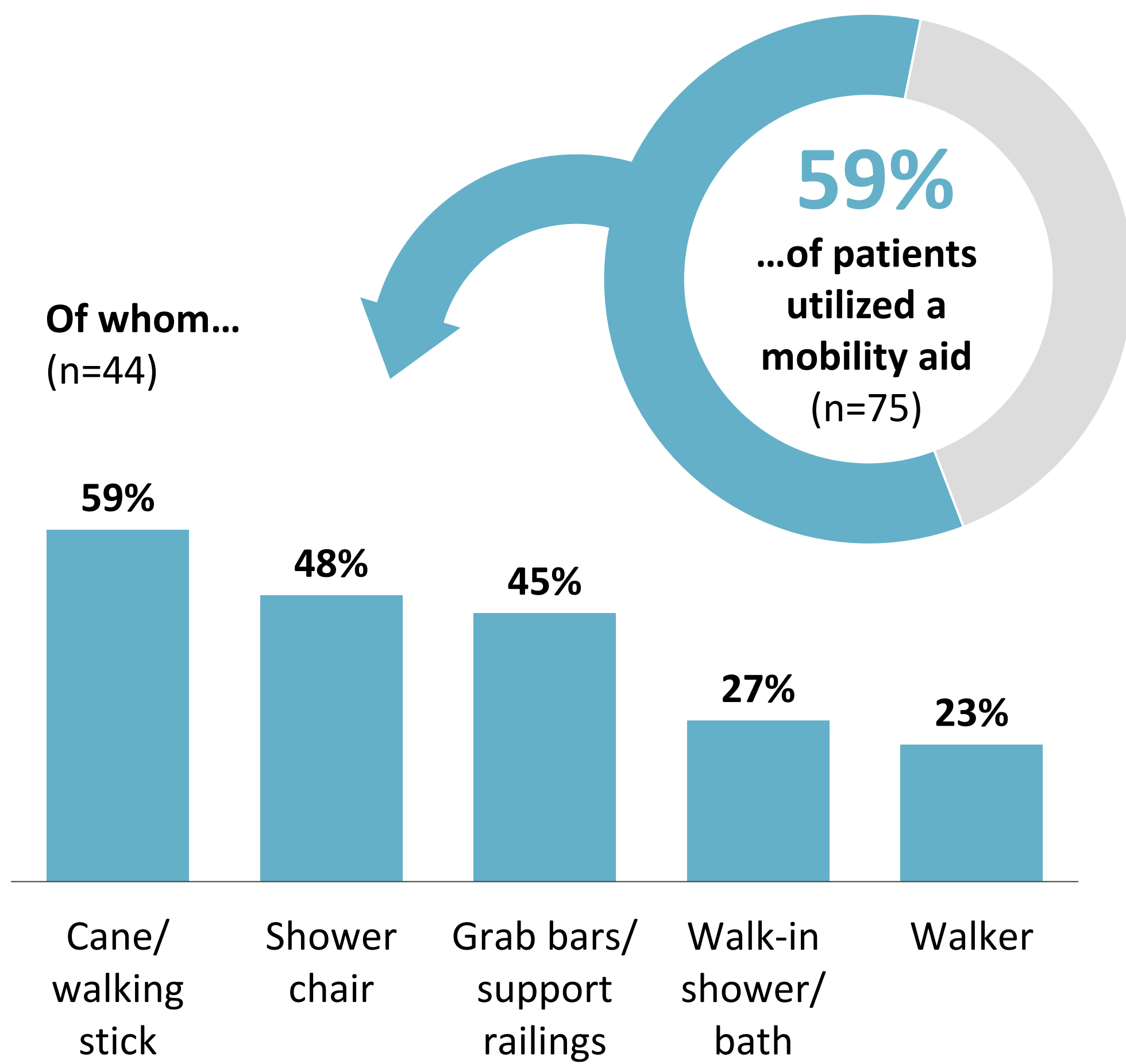


Figure 3. Mobility aids used (top 5)



### 3. Physical impairment and employment status

- The I-RODS measured the degree of disability in patients by having them assign a score between 0 (impossible to perform) and 2 (easily performed) to 24 items describing daily activities. Patients' (n=65) mean (SD) centile I-RODS score was 66.7 (22.9).
- Figure 4** shows the 6 daily activities, out of 24, that were the most difficult for patients to perform.
- Many were unemployed, retired, on long term sick leave or working part time (**Figure 5**).

Figure 4. Most difficult activities (top 6)

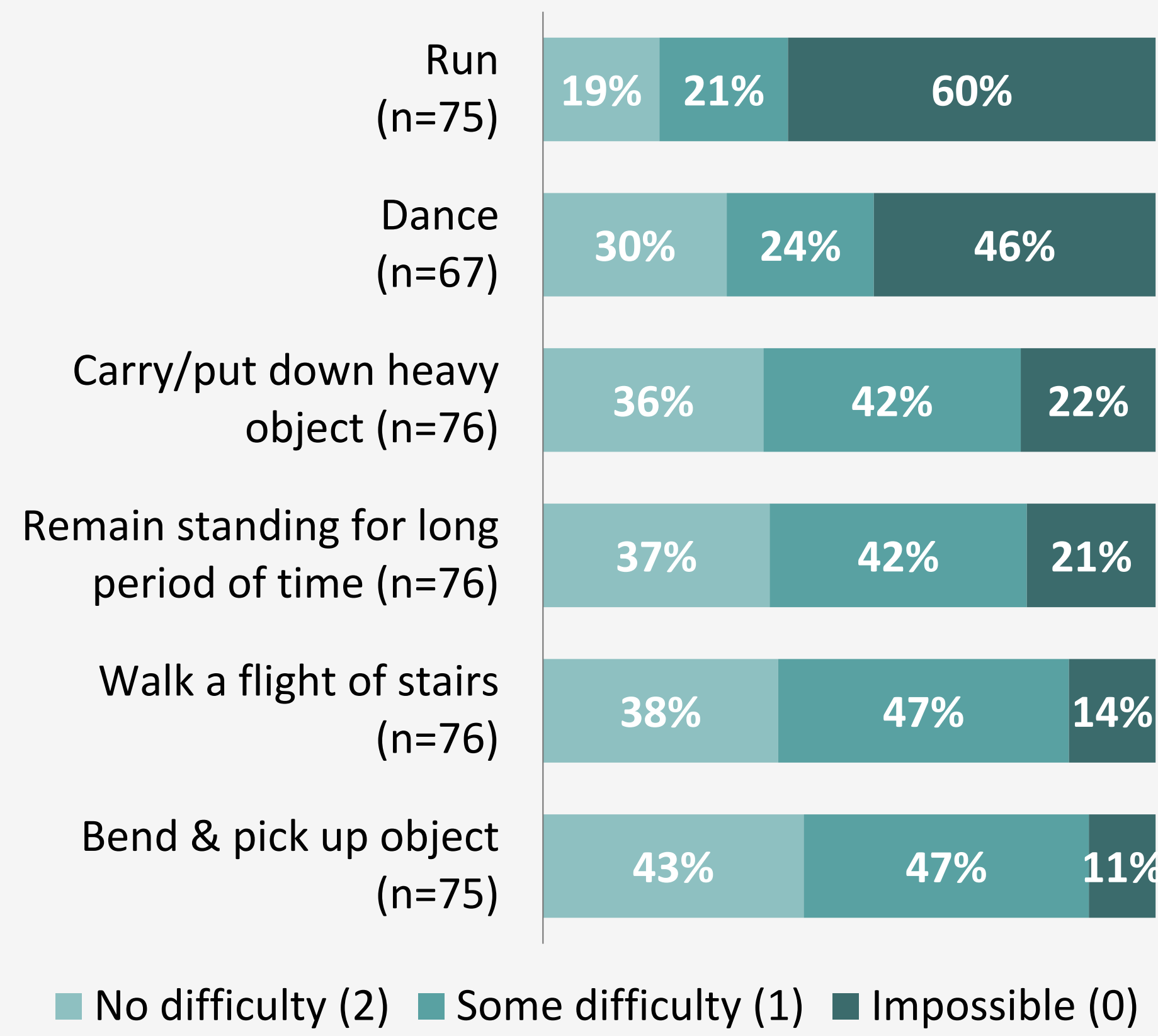
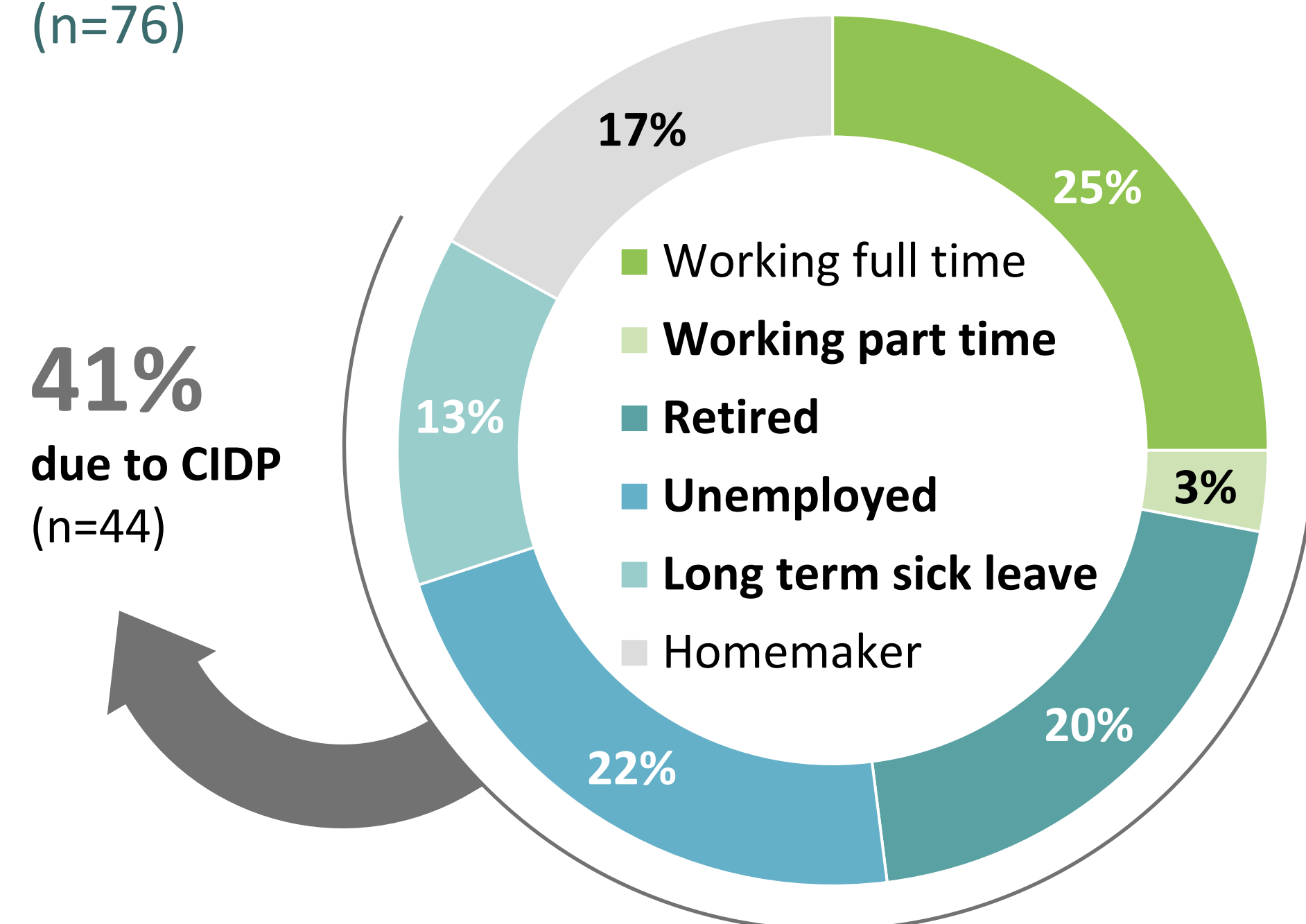


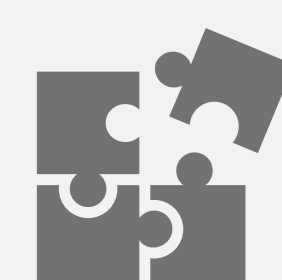
Figure 5. Employment status (n=76)



## Conclusions

CIDP imposes a **substantial burden** on patients, limiting their ability to work and perform daily activities. As a result, many require caregiver assistance and mobility aids.

Despite treatment goals of improving QOL and physical functioning while reducing pain and fatigue, many treated patients with CIDP continue to experience **moderate-to-severe symptoms**.



Further research is needed to better understand the needs of CIDP patients and how they can be managed.