P 417

Life-Altering Consequences of Guillain-Barré Syndrome: Significant Unmet Need for Timely Diagnosis and Appropriate Treatment

Bart Jacobs[1], Eveline Wiegers[1], Behn Sarafpour[2], Bismay Mishra[2], Chelsey Fix[3], Mark Solomon[4], Mark Rushek[5], Jeffrey A. Allen[6]

Presented by Pallavi Lacey[2] on behalf of the authors

[1]Erasmus MC, University Medical Center Rotterdam, Rotterdam, The Netherlands; [2]Annexon Biosciences, Brisbane, CA, USA; [3]GBS-CIDP Foundation International, Conshohocken, PA, USA; [4]Archstone Insights, San Francisco, CA, USA; [5]Basis Research, Chicago, IL, USA; [6]University of Minnesota, Minneapolis, MN, USA

Introduction

- Guillain-Barré syndrome (GBS) is a rare, life-threatening, rapid-onset, neuromuscular emergency with life-altering residual symptoms[1,2]
- GBS remains poorly understood and represents a substantial burden for patients, families, and the healthcare system[1]

Aim

- To comprehensively understand the GBS patient journey, including:
  - Key patient experiences during each stage of GBS
  - Impact of GBS on patients' lives: physically, emotionally, financially and professionally
  - Unmet needs with treatment and gaps across various stages of GBS management

Methods

- US-based GBS survivors and their care partners recruited via GBS/CIDP Foundation International underwent 60-minute, live, online video interviews
- Symptom presentation, diagnosis, hospitalization, in-patient rehabilitation, discharge and long-term impact were discussed

Results

- In January 2025, 27 GBS survivors and 6 care partners were interviewed (**Table**)

Table. Patient and care partner sample demographics

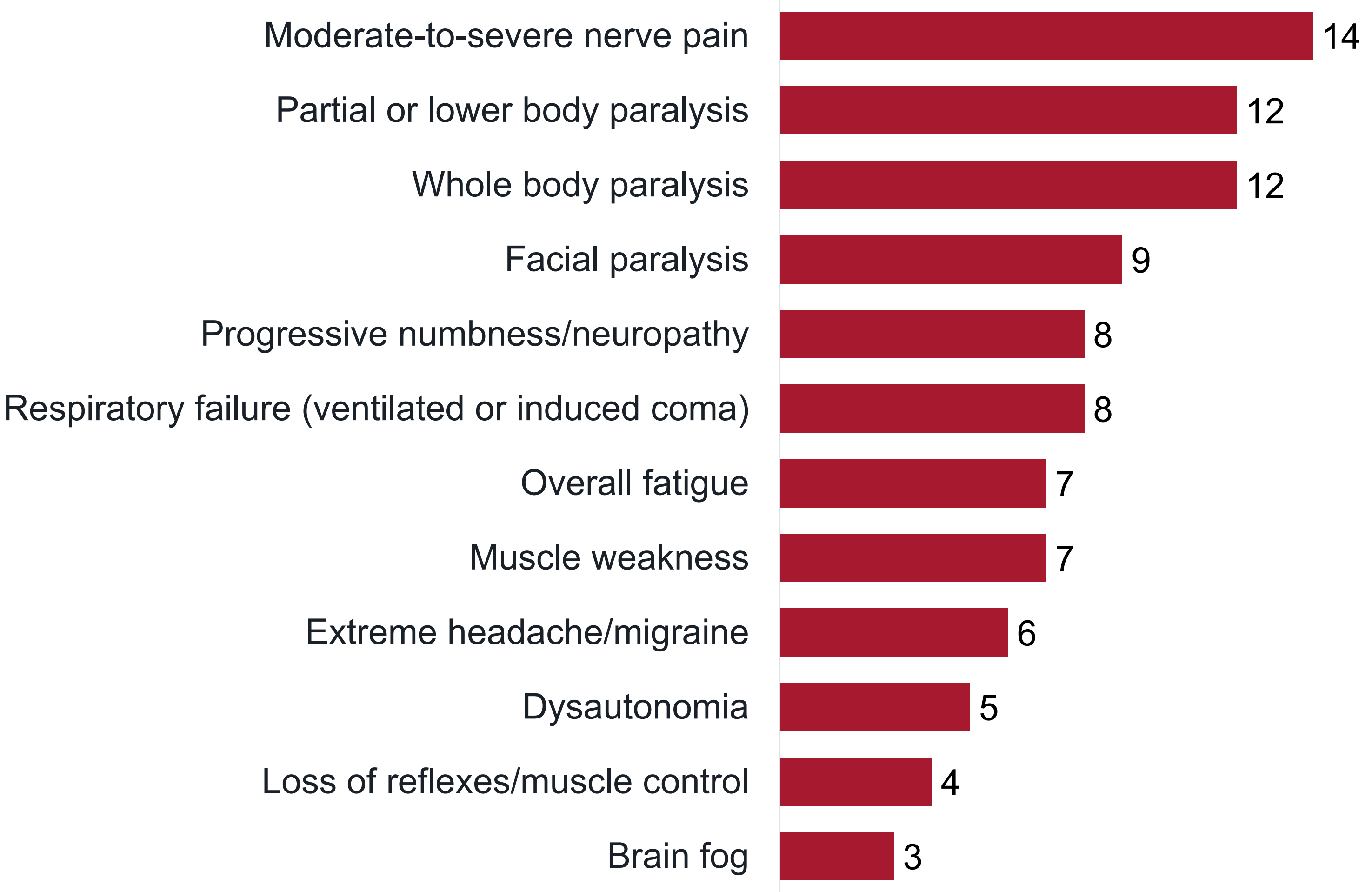
Characteristic, n (%)	N=33
Participants	
GBS patients	27 (82)
Care partners	6 (18)
Age group, years	
21–29	2 (6)
30–49	8 (24)
50–64	13 (39)
65–69	5 (15)
70+	5 (15)
Sex	
Female	19 (58)
Male	14 (42)

Symptom Presentation

- Initial GBS symptoms were highly variable yet potentially debilitating, ranging from mild muscle weakness to severe symptoms, including total paralysis and respiratory failure requiring ventilation (**Figure 1**)
- Most patients reported moderate symptoms

> *"[The patient] had intense fear, thinking, 'What is going on with my body!' Respiratory failure was like a near-death experience"*
>
> **Care Partner**

Figure 1. Most common initial symptoms (number of mentions)



Diagnosis

- Patients expressed feelings of fear, confusion and anxiety at diagnosis and highlighted a need for increased GBS awareness among healthcare professionals (HCPs)
- Patients experienced significant diagnostic delays:

24% diagnosed at presentation

58% diagnosed >2 weeks after presentation

66% initially misdiagnosed

- Diagnostic delays were due to multiple factors: lack of patient urgency, low symptom severity at onset, high symptom severity leading HCPs to suspect other conditions, slow symptom progression, lack of diagnostic clarity and/or HCPs lacking awareness of GBS

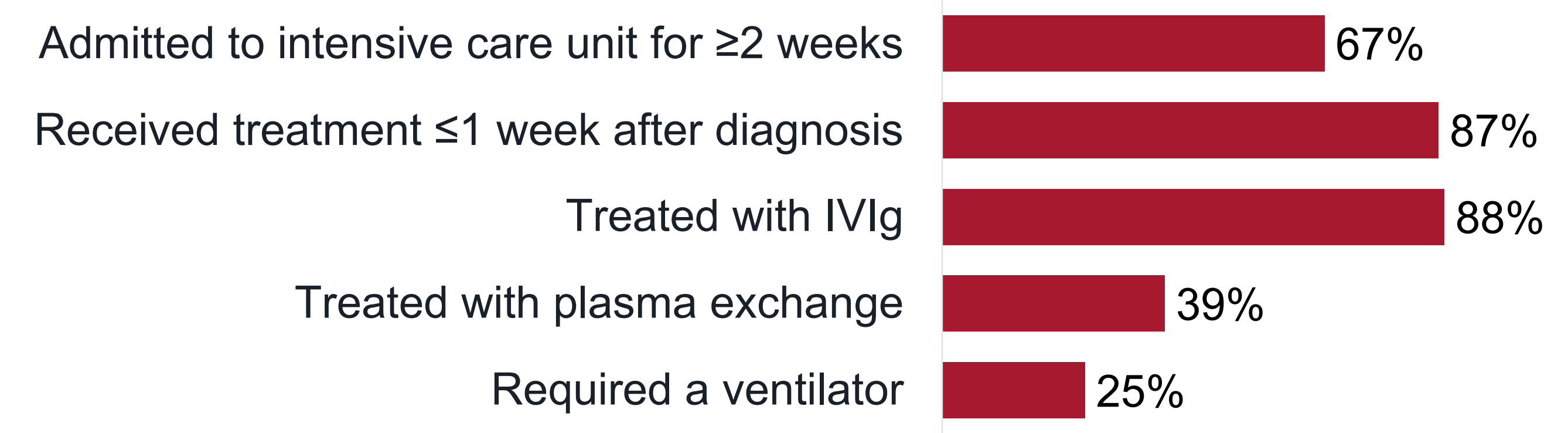
> *"The neurologist thought it was alcohol related. I was in the hospital for a month before GBS was diagnosed"*
>
> **Patient**

Hospitalization and Treatment

- **Figure 2** summarizes the elements of treatment received
- Patients reported fragmented and disjointed care and encountered multiple specialists. This resulted in confusion for patients and minimal opportunities to develop a rapport with HCPs

> *"They did five IVIg treatments. I was on as much pain medication as they could give me, and I still couldn't handle feeling a wrinkle in the sheets"*
>
> **Patient**

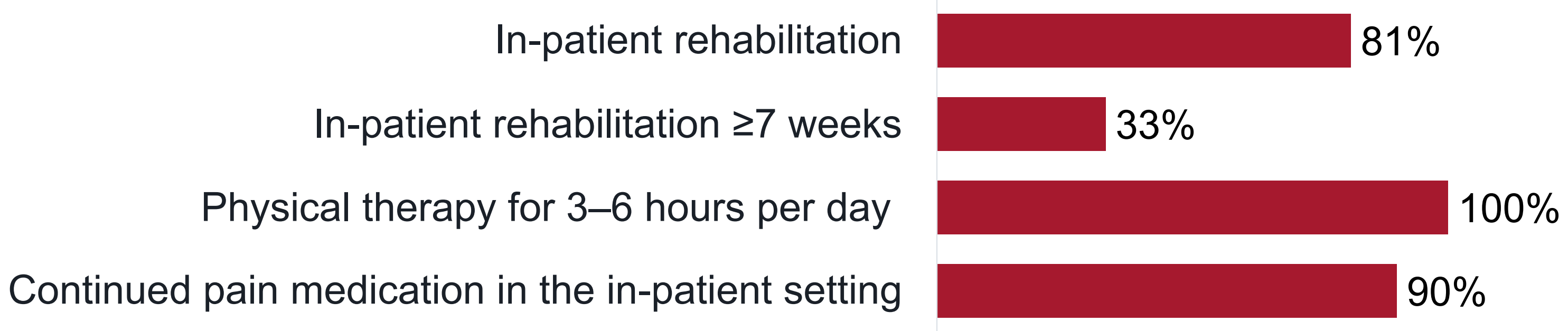
Figure 2. Intensive care and treatment



In-Patient Rehabilitation

- Most patients underwent in-patient rehabilitation (**Figure 3**)

Figure 3. Rehabilitation



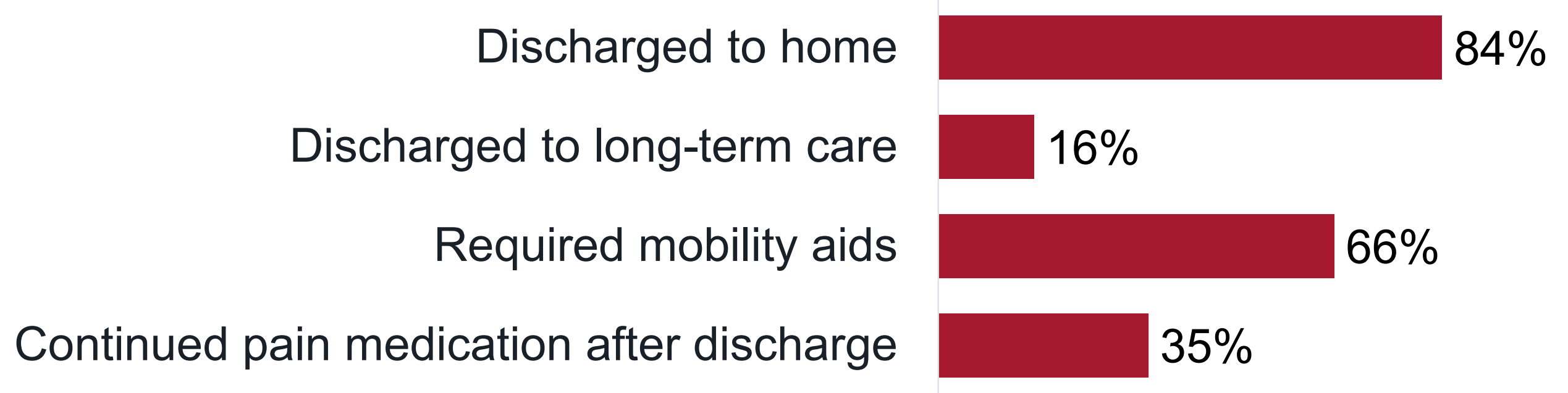
- Patients experienced a spectrum of emotions during intensive rehabilitation. From initial feelings of vulnerability, patients used warrior and battle imagery to describe the work and determination required to regain strength and muscle control. They reported being overwhelmed by slow progress before finally overcoming their challenges

> *"They need to tell people it takes a long time to recover, and it is hard work"*
>
> **Patient**

Discharge

- Upon discharge (**Figure 4**), patients continued to work towards recovery and reported feelings of relief, uncertainty, frustration and anxiety alongside continued pain, and functional and intimacy issues

Figure 4. Discharge



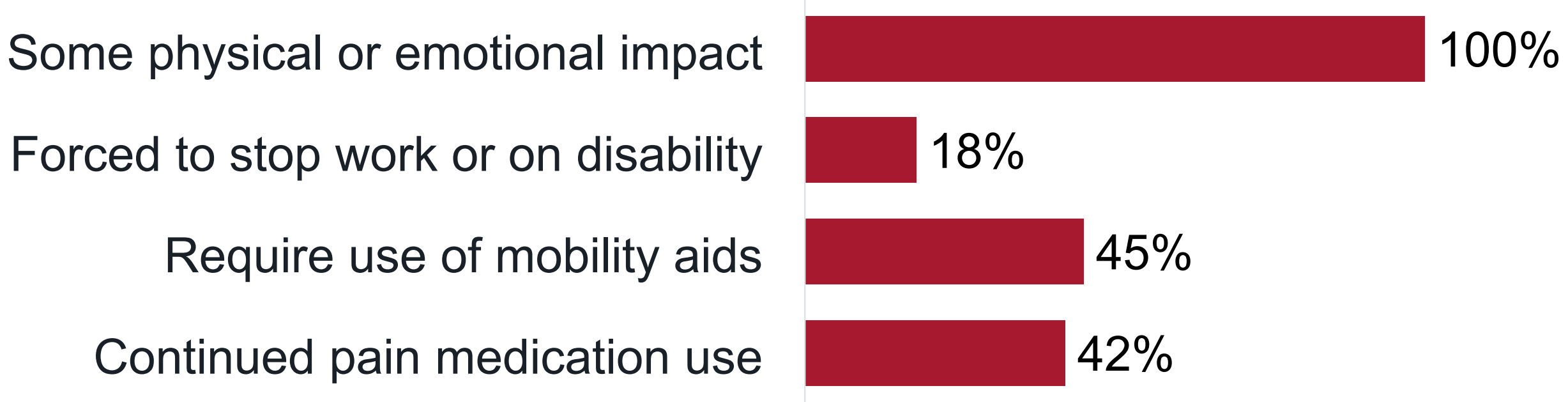
> *"It's 13 steps up to the bedroom. He sat down in the middle of the stairs crying – he couldn't make it"*
>
> **Care Partner**

> *"It didn't look like I would be able to resume pre-diagnosis life"*
>
> **Patient**

Long-Term Impact

- Patients reported long-term physical, functional and emotional impacts (**Figure 5**). Many patients could no longer do their jobs. Patients also reported social loss and isolation

Figure 5. Long-term impact



Financial Impact

- Average hospital bills were $220,000–285,000, with some patients and caregivers facing financial hardship

CONCLUSIONS

- GBS is a potentially life-altering illness that requires patient-centred solutions
- More accurate and rapid diagnosis, better coordinated care, more efficacious treatments, and long-term support systems are required to improve the patient experience and answer the unmet needs for patients and their caregivers throughout the patient journey

References
1. Leonhard SE, et al. *Nat Rev Dis Primers.* 2024;10(1):97. 2. Willison HJ, et al. *Lancet*. 2016;388:717–27.

Acknowledgments
The study was sponsored by Annexon Biosciences (Brisbane, CA, USA). Medical writing and editing assistance were provided by Envision Ignite, an Envision Medical Communications agency, a part of Envision Pharma Group, and were funded by Annexon Biosciences.

Disclosures
BJ: Funding for research or consultancy from Prinses Beatrix Spierfonds, GBS-CIDP Foundation International, NIH, EU Horizon, Sanquin, Grifols, CSL-Behring, Annexon, Hansa Biopharma, Roche, Octapharma, argenx. EW: Nothing to disclose. BM, PL: Employees and shareholders of Annexon Biosciences. BS, Employee and shareholder of Annexon Biosciences at the time of the study. CF: Employee of GBS-CIDP Foundation International. MS: Employee of Archstone Insights. MR: Employee of Basis Research. JAA: Consultant fees: Akcea therapeutics, Alexion, Alnylam Pharmaceuticals, Annexon Biosciences, argenx, CSL Behring, Grifols, Immunovant, Immupharma, Johnson & Johnson, Pfizer, and Takeda. Previously accepted and presented at the American Academy of Neurology Annual Meeting 2026.

Presented at the 2026 Peripheral Nerve Society Annual Meeting, 13–16 June 2026, Maastricht, The Netherlands