

Acute and chronic life-altering consequences of Guillain-Barré syndrome: A qualitative study identifies significant unmet need for timely diagnosis and appropriate treatment

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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 system¹

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 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. Most (n=20) had private medical insurance (Table 1)

Table 1. Sample demographics

Characteristic, n (%)	N=33
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)
Insurance	
Private	20 (61)
Other (Medicare, Affordable Care Act, Medicaid)	13 (39)

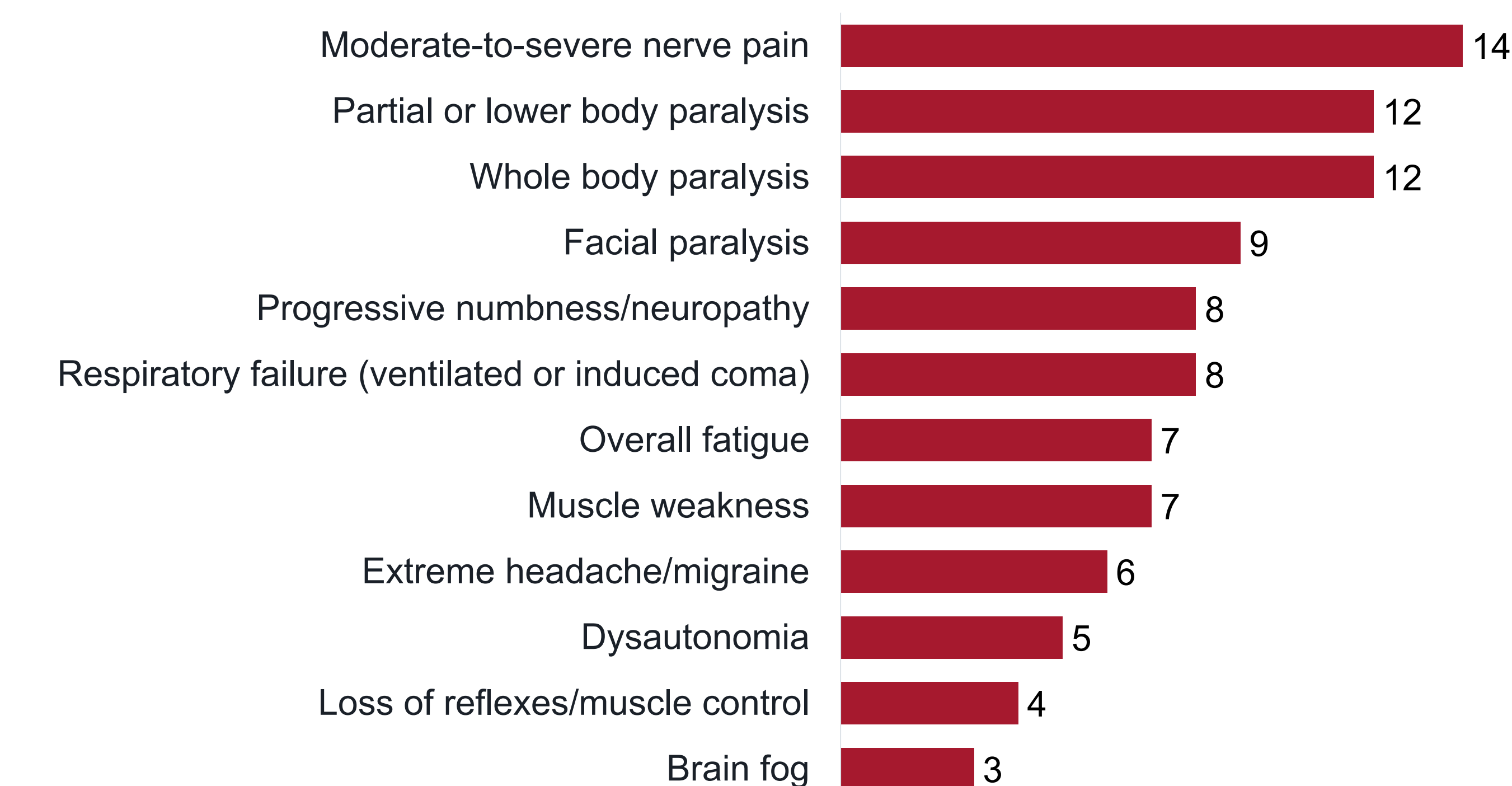
Symptom Presentation

- 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 ”

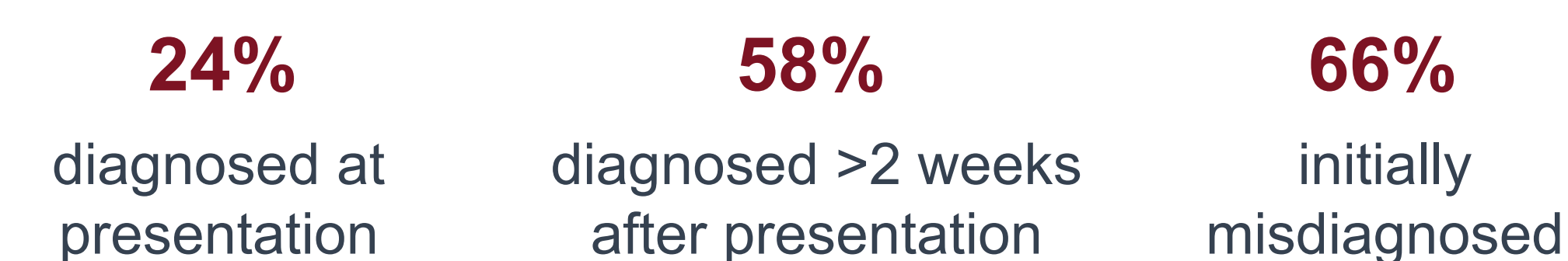
Care Partner

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:



CONCLUSIONS

- GBS is a potentially life-altering illness that requires patient-centered 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 care givers throughout the patient journey

- 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

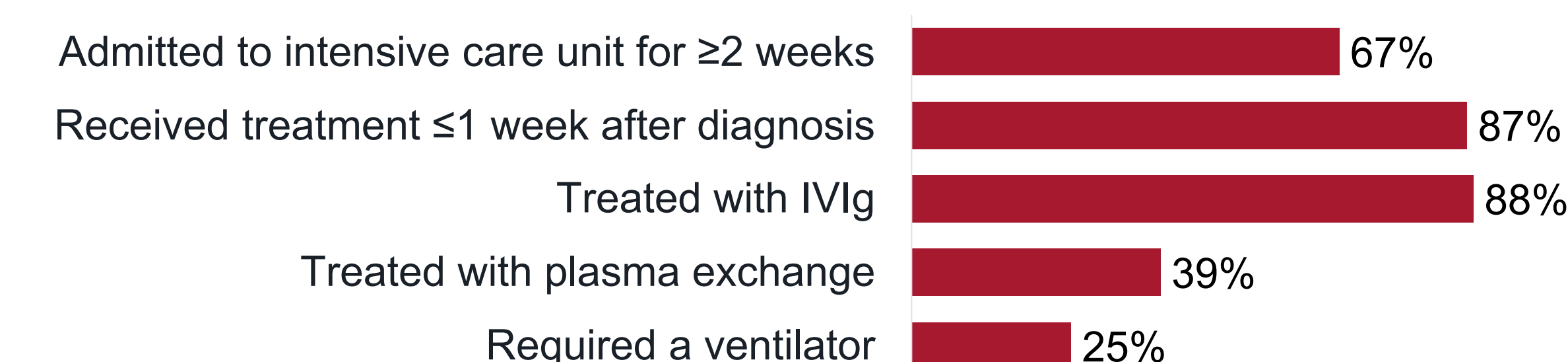
Hospitalization and Treatment

- 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 made it seem like IVIg was the silver bullet. But I began losing hope because it wasn't doing anything ”

Patient

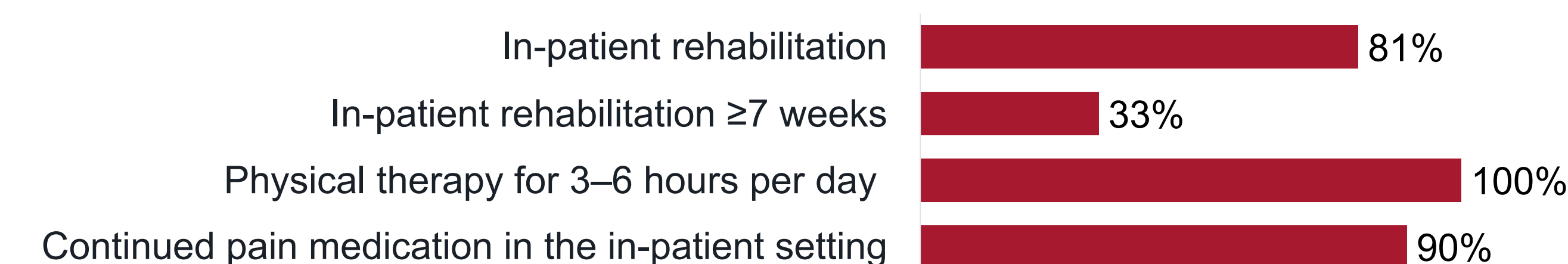
Figure 2. Treatment



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

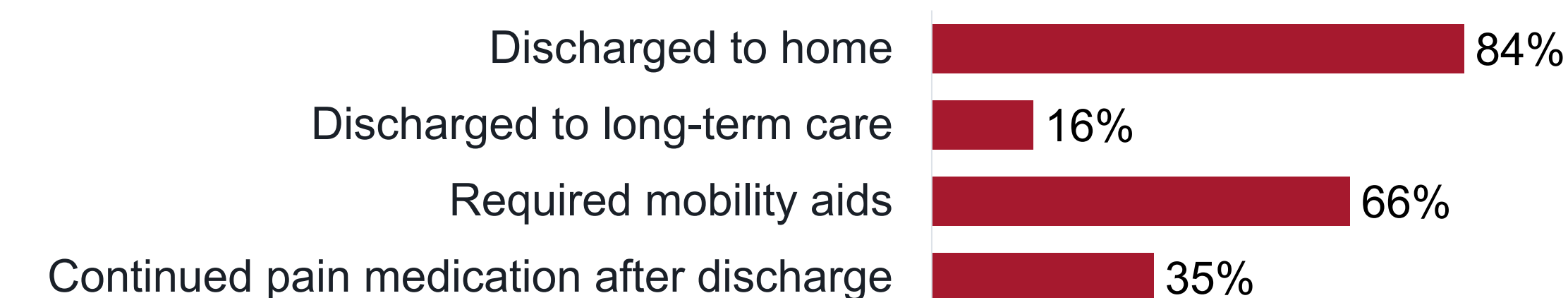
“ They need to tell people it takes a long time to recover, and it is hard work ”

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 care givers facing financial hardship

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

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