Hidden Burden of Guillain-Barré Syndrome (GBS): A US Survey of Patients and Care Partners

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Objective

- Guillain-Barré Syndrome (GBS) is a rare, immune-mediated polyradiculoneuropathy and the leading cause of acute flaccid paralysis globally[1,2]
- GBS imposes substantial burden on patients with high mortality and increased healthcare resource utilization (HCRU), including prolonged hospitalization and extended rehabilitation needs[1-3]
- Long-term physical, psychosocial, and occupational impacts are common following GBS, with many patients experiencing persistent disability, fatigue, reduced quality of life, and lasting changes in employment, hobbies, and social participation years after diagnosis[4-10]
- Despite growing evidence of long-term burden, the patient- and care partner-level economic impact of GBS in the United States (US) remains undercharacterized
- This study is part of a broader effort to comprehensively characterize the burden of GBS in the US and aims to quantify the financial and caregiving burden experienced by patients with GBS and their unpaid care partners

Methods

- Qualitative Interviews (n=28): Patients, care partners, clinicians, payers and P&T members; informed survey design
- Cross-Sectional Web Survey (US, 2025): 65 adults with clinician-confirmed GBS + 15 unpaid care partners; captured HCRU, direct non-medical costs, and lost productivity/caregiving burden
- Claims Analysis (2018–2025): Commercial + Medicare 5% Standard Analytic Files (SAF) data; 2,297 patients (Year 1), 1,366 (Year 2); estimated patient out of pocket (OOP) costs
- Descriptive Analyses: Characterized HCRU, employment impacts, caregiving burden, and costs at ≤12 months and >12 months post-discharge (index= primary hospitalization for GBS)

Sample Demographics

Table 2. Survey & Claims Data Sample Characteristics

Web Survey Sample Characteristics	Patients (N=65)	Care partners (N=15)
Age at index*, mean (SD) years	49.3 (14.2)	58.0 (11.7)
Male sex, n (%)	18 (28)	6 (40)
Patients with a care partner	54 (83)	–
ICU requirement, n (%)	36 (55)	–
Mechanical ventilation requirement, n (%)	21 (32)	–
Functional status at index, n (%)		
Symptoms in arms or legs, but walking not affected	2 (3)	–
Walking was not normal, but could walk without assistance	5 (8)	–
Able to walk, but only with assistance	11 (17)	–
Unable to walk (bedridden/chair-bound)	47 (72)	–
Functional status at discharge, n (%)		
Symptoms in arms or legs, but walking not affected	2 (3)	–
Walking was not normal, but could walk without assistance	7 (11)	–
Able to walk, but only with assistance	21 (32)	–
Unable to walk (bedridden/chair-bound)	35 (54)	–
Claims Data Characteristics	**Patients (N=2,297)**	–
Age at index, mean (SD) years	49.4 (10.7)	–
Male sex, n (%)	1,244 (54)	–

In the survey:

- Most patients (83%) reported having an unpaid care partner, highlighting the substantial caregiving needs associated with GBS recovery
- Disease severity was high within the study population, with over half of patients requiring ICU admission and nearly one-third requiring mechanical ventilation during hospitalization
- There was pronounced functional impairment at both index hospitalization and discharge; most patients remained unable to walk independently at discharge, indicating persistent ongoing rehabilitation and support needs

For the claims analysis:

- The claims analysis included 2,297 patients with GBS; mean age at index hospitalization was similar to the survey cohort, though the claims population included a higher proportion of male patients

**Index = index hospitalization for GBS*

HCRU Post-Discharge & Corresponding OOP Costs

Figure 1. GBS Patient-reported Medical Care Utilization Post-Discharge (Survey)

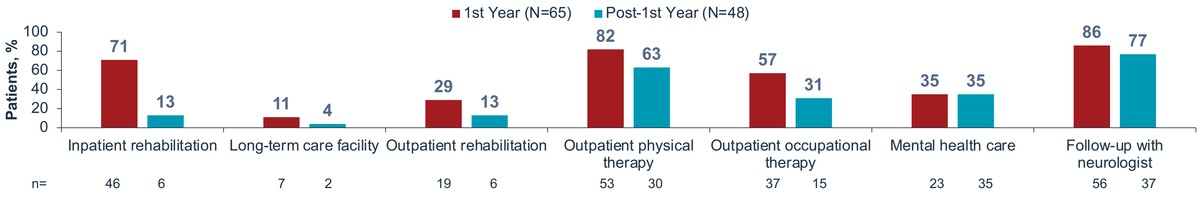


Table 2. Average OOP Costs for Direct Medical Expenses (Claims)

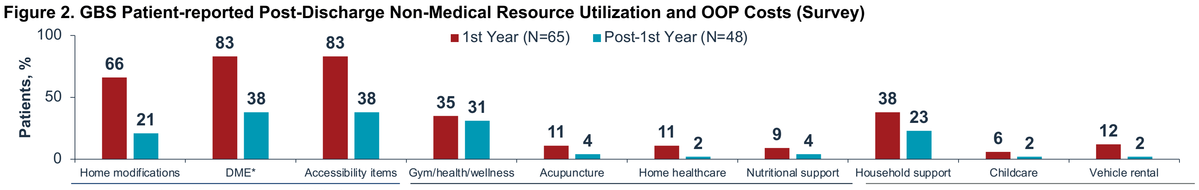
	Year 1 (n=2,297)			Year 2 (n=1,366)		
	Utilization (n)	Utilization (%)	OOP	Utilization (n)	Utilization (%)	OOP
Index Hospitalization	2297	100%	$1,601			
GBS-Related Acute Inpatient**	414	18%	$254	70	5%	$133
GBS-Related Inpatient Rehabilitation	681	30%	$173	< 17*	<1%	$4
GBS-Related Long-Term Care	105	5%	$370	2	0%	$-
GBS-Related Skilled Nursing Facility	179	8%	$578	<14*	<1%	$37
GBS-Related Emergency Department	82	4%	$3	<27*	<2%	$4
GBS-Related Office	1455	63%	$110	438	32%	$66
GBS-Related Outpatient Rehab (PT/OT)	798	35%	$168	90	7%	$49
Total GBS-Related Medical Care	1795	78%	$1,803	607	44%	$462

**Cell counts suppressed per Medicare data reporting requirements; **Acute inpatient defined as a stay at an inpatient hospital (place of service code: 21)*

- The most commonly utilized services following index hospitalization were neurologist follow-up visits and outpatient physical therapy
- Average patient OOP costs for total GBS-related medical care were approximately $1,800 (2025 USD) during the first year following hospitalization, indicating ongoing financial burden beyond the index admission
- The total average patient OOP inclusive of index hospitalization and first year following hospitalization was $3,010 (2025 USD)
- Skilled nursing facility care was associated with the highest patient OOP costs post-discharge ($578 per patient utilizing care), followed by long-term care and acute inpatient care
- A notable proportion of patients continued to require GBS-related care, and incurred some OOP expenses beyond the first year post-discharge suggesting ongoing morbidity and disability

Direct Non-Medical Resource Utilization & Corresponding OOP Costs

Figure 2. GBS Patient-reported Post-Discharge Non-Medical Resource Utilization and OOP Costs (Survey)



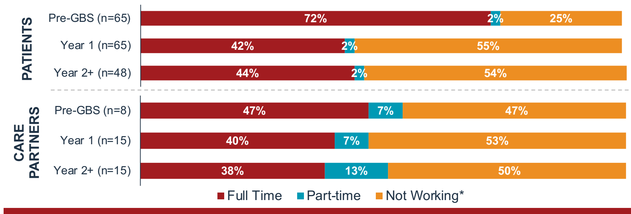
	Equipment, modification and accessibility items	Health and wellness-associated costs				Household support care/services		
	Mean equipment, modifications, accessibility OOP (SD)	Mean gym/health/ wellness OOP (SD)	Mean Acupuncture OOP (SD)	Mean Home healthcare OOP (SD)	Mean Nutritional support OOP (SD)	Mean Household support OOP (SD)	Mean Childcare OOP (SD)	Mean Vehicle rental OOP (SD)
1st Year (N=65)	$1924.1 ($3584.8)	$251.8 ($568)	$59 ($210.6)	$200.1 ($929.8)	$48.6 ($329.2)	$642.4 ($1228.2)	$7.8 ($45.3)	$213.9 ($761.8)
Post-1st Year (N=48)	$273.2 ($561.1)	$159.2 ($403.5)	$101.2 ($639.4)	$21.4 ($148.5)	$11.3 ($55.7)	$763.7 ($2919.8)	$0 ($0)	$9.5 ($65.7)

- The most commonly reported non-medical expenses were durable medical equipment (DME), accessibility items, and home modifications, reflecting the persistent functional limitations during recovery; these items also generated the highest average OOP cost during the first year post-discharge
- Many patients also reported gym/wellness and household support expenses, reflecting prolonged rehabilitation and caregiving needs
- Large standard deviations across cost categories suggest considerable variability in financial burden, with some patients experiencing exceptionally high non-medical expenses
- Although utilization and costs generally declined after the first year, more than one-third of patients continued to report equipment and accessibility-related costs, indicating persistent morbidity and disability beyond the acute recovery period

**DME= durable medical equipment*

Change in Employment Status & Income Loss

Figure 3. GBS Patient- and Care Partner-reported Change in Employment Status & Lost Wages (Survey)



Mean Lost Wages of Affected Patients (SD):**
Year 1 (n=44): $41,491 ($41,994.7)
Year 2+ (n=32): $45,668.6 ($45,604.6)

Mean Lost Wages of Affected Care Partners (SD):**
Year 1 (n=7): $38,164.5 ($60,893)
Year 2+ (n=5): $66,121 ($115,970.8)

- Among patients, the proportion not working more than doubled during the first year of recovery and remained elevated into the second year
- Care partners also experienced workforce impacts, including reductions in full-time employment and increases in part-time work or workforce exit
- Employment and income losses persisted beyond the first year following index hospitalization, suggesting long-term occupational and financial impacts associated with ongoing morbidity and caregiving needs

Conclusions

- Total mean direct medical out-of-pocket costs for patients with GBS was $3,010 inclusive of index hospitalization and all GBS related care in the 12 months after hospital discharge
- GBS was associated with prolonged clinical and economic burden for both patients and unpaid care partners beyond the index hospitalization
- Patients continued to require rehabilitation, neurologic follow-up, and supportive care, contributing to ongoing HCRU and OOP expenses
- Non-medical expenses related to DME, accessibility modifications, transportation, and household support represented a major component of financial burden (i.e., OOP costs)
- GBS also resulted in workforce disruption and major wage losses among both patients and care partners
- These findings provide a more comprehensive understanding of the patient- and household-level burden of GBS in the US and highlight the need for improved supportive care and more effective treatment strategies

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