Guillain-Barré Syndrome (GBS) Is Associated With Substantial Mortality Burden: A US Claims-Based Study of Individuals Hospitalized with GBS

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Introduction

- Guillain-Barré syndrome (GBS) is a rare, immune-mediated peripheral neuropathy with acute flaccid paralysis and autonomic dysfunction[1,2]
- While the acute disease process last weeks it can lead to substantial morbidity and mortality in the following months and years[1-2]
- Previous studies have reported in-hospital mortality rates of 2-4% in the US and EU, with up to 20% among patients with dysautonomia or requiring mechanical ventilation[3-6]
- However, contemporary real-world data from the United States (US) remain limited

Objectives

- Characterize the disease burden among adults hospitalized with GBS in the US
- Establish mortality among adults with GBS during the index hospitalization and first year of follow-up

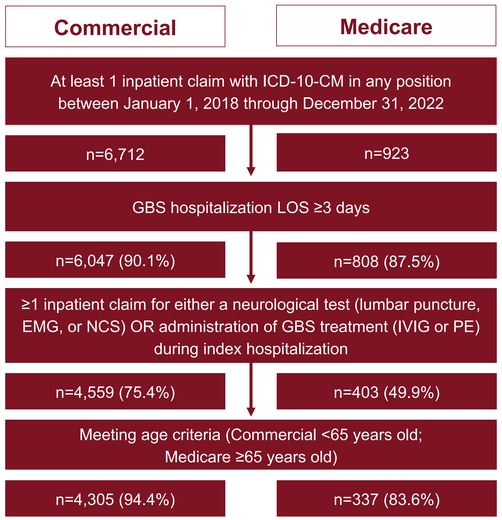
Methods

- A retrospective study using a claims database of commercially insured [“Commercial”] and Medicare Fee-For-Service 5% Standard Analytic Files (SAF) [“Medicare”] covering Jan 1, 2018 through Dec 31, 2023, with a 12-month pre-period from Jan 1, 2017 through Dec 31, 2017 of no GBS diagnoses
- A modified version of the previously validated algorithm was used to identify patients[7] (**Figure 1**). This included GBS diagnosis (International Classification of Diseases, 10th Revision, Clinical Modification [ICD-10-CM] G61.0), GBS hospitalization length of stay (LOS) ≥3 days, and patients needed to have either a neurological test or treatment (immunoglobulin and/or plasmapheresis) on an inpatient claim
- Annual incidence rates were estimated and projected to the 2025 US populations aged ≥65 and <65 years
- Mortality estimates during index GBS hospitalization and 12 months post-discharge, were age- and sex-adjusted and projected to 2025
  - Commercial claims data were used to estimate incidence and mortality among patients with GBS aged <65 years; death was defined using the validated claims-based algorithm[8-10]
  - Medicare data were used to estimate incidence and mortality among patients with GBS aged ≥65 years; in the 5% SAF, death was defined using the recorded death date

Results

- Between 2018 and 2022, a total of 4,305 commercially insured and 337 Medicare FFS beneficiaries met the study inclusion criteria (**Figure 1**)
- The combined age- and sex-adjusted annual GBS incidence, standardized to the 2025 US population, was 2.39 (95% CI: 2.28–2.47) cases per 100,000 individuals, corresponding to an estimated 8,039 cases (7,734–8,364) annually
- The incidence rate was approximately two-fold higher among individuals aged ≥65 years (4.17 [3.71–4.60]) compared to <65 years (1.97 [1.91–2.03])

Figure 1. Study sample selection and attrition



EMG, electromyography; IVIG, intravenous immunoglobulin; NCS, nerve conduction study; PE, plasmapheresis.

- Mean time of index hospitalization (standard deviation) was 12.9 days (18.1) in Commercial population and 13.2 (10.9) days in Medicare beneficiaries, with 27.6% of Commercial and 35.9% of Medicare receiving intensive care unit (ICU) care (**Table 1**)

Table 1. Patient characteristics and healthcare resource utilization during the index hospitalization

	Commercial (N=4,305)		Medicare (N=337)	
Age at index, years				
Mean, SD	43.4	15.5	73.1	6.3
Median	47		72	
25th, 75th percentiles	33	57	68	77
Min, Max	0	64	65	93
Male	2,200	51.1%	207	61.4%
Quan Charlson Comorbidity Index				
Mean, SD	1.3	1.8	2.2	2.5
Median	0		2	
25th, 75th percentiles	0	2	0	4
Min, Max	0	12	0	12
Kim Frailty Index				
Robust	911	21.2%	74	22.0%
Pre-frail	2,732	63.5%	189	56.1%
Mild frailty	599	13.9%	60	17.8%
Moderate-to-severe frailty	63	1.5%	14	4.2%
Total LOS, days				
Mean, SD	12.9	18.1	13.2	10.9
Median	8		10	
25th, 75th percentiles	5	14	6	16
Min, Max	3	551	3	74
ICU stay				
Any ICU stay	1,189	27.6%	121	35.9%
Mean, SD ICU LOS (days)	8.7	16.0	8.8	11.9
Median	3		5	
25th, 75th percentiles	0	12	0	13
Min, Max	0	241	0	63
Breathing support				
Any breathing support	481	11.2%	71	21.1%
MV	466	10.8%	71	21.1%
ECMO	8	0.2%	0	0.0%
Tracheostomy	275	6.4%	29	8.6%

ECMO, extracorporeal membrane oxygenation; LOS, length of stay; MV, mechanical ventilation; SD, standard deviation.

- Among those aged <65 years, estimated in-hospital mortality was 1.8% (1.4–2.1%); 12-month mortality increased to 5.1% (4.5–5.8%) **(Table 2)**, which was 16.3 times higher than the average annual mortality of a 45-year-old[11]
- Among those aged ≥65 years, estimated in-hospital mortality was 7.7% (4.9–10.6%); 12-month mortality reached up to 24.0% (19.5–28.6%), which was 10.6 times higher than the average annual mortality of a 70-year-old[11]
- Across both populations, higher mortality rates were observed during the years of the COVID-19 pandemic (2020–2022)

Table 2. Mortality rates among patients with GBS during the index hospitalization or during the 12-month follow-up (projected to 2025 US population)

	Aged <65 years			Aged ≥65 years		
	Deaths, n	GBS cases, n	Mortality rate (95% CI)	Deaths, n	GBS cases, n	Mortality rate (95% CI)
Death during index hospitalization[1]						
	476	27,046	1.8% (1.4–2.1%)	1,017	13,143	7.7% (4.9–10.6%)
Death during index hospitalization OR during the first 12 months after discharge (first follow-up year[a])						
	1,385	27,046	5.1% (4.5–5.8%)	3,159	13,143	24.0% (19.5–28.6%)
Annual mortality rates by year[b]						
2018	234	5,439	4.3% (3.0–5.6%)	660	2,793	23.6% (13.8–33.4%)
2019	229	5,632	4.1% (2.8–5.4%)	460	2,643	17.4% (8.4–26.3%)
2020	241	4,771	5.0% (3.5–6.6%)	696	2,743	25.4% (15.2–35.5%)
2021	373	5,421	6.9% (5.3–8.5%)	670	2,167	30.9% (18.7–43.1%)
2022	305	5,783	5.3% (3.9–6.7%)	677	2,797	24.2% (14.2–34.2%)

[a]Calculated as (number of GBS cases who died in the time frame / total number of GBS cases with sufficient follow-up) * 100%. [b]Calculated as (number of GBS patients who died within 12 months / total number of GBS patients diagnosed in that year) * 100%.

Limitations

- Potential inaccuracies in GBS diagnostic coding, as reported in prior studies[3-6], may result in under- or over-estimation of incidence and mortality cases
- Variability in coding practices limits the accurate characterization of inpatient details

CONCLUSIONS

- Although GBS is typically regarded as a monophasic illness with a generally favorable prognosis, our findings highlight a significant risk of mortality within the first year following diagnosis, extending beyond the index-hospitalization period
- Individuals with GBS face significant morbidity and mortality due to their illness, particularly among those aged 65 or older
- Among patients <65 years, mortality rates trended higher than previously reported before the COVID pandemic (>4%) and during the same period, those ≥65 years had rates reported closer to 20%
- These observations imply that there is an urgent need for more effective acute-stage treatments that can mitigate long-term GBS-associated morbidity and mortality

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