

Describing the Population of Patients With Prolonged Seizures: US Subgroup Results From a Global Real-World Point-in-Time Study

Background

- Despite the use of antiseizure medications, approximately one-third of people living with an epilepsy (PwE) continue to experience seizures¹; these seizures may become prolonged and/or progress to more severe seizure types (eg, convulsive seizures, seizure clusters [SCs], status epilepticus [SE]).
- Given the uncertainty as to whether seizures will become prolonged and progress to severe seizure types, PwE who experience prolonged seizures (PS) are very likely to worry about having a seizure.
- PS may be associated with a lower quality of life, loss of productivity, and high seizure-related healthcare resource utilization (HCRU), as well as indirect costs due to PwE with PS being unable to work.
- PS may also be associated with an increased risk of injury, need for emergency services, hospitalization, brain injury, and death.
- However, there remains a gap in the literature on PS, and the population of PwE with PS remains not well characterized.

Objective

- To describe PwE characteristics, treatment patterns, HCRU, and overall disease burden, including work impairment and seizure worry, among PwE who experience PS in the United States.

Methods

- Data were drawn from Adelphi's PS Disease Specific Programme™ (DSP), a real-world point-in-time survey (RWE0807) conducted in China, France, Germany, Italy, Japan, Spain, the United Kingdom, and the United States between March 2023 and February 2024.
- Ethics approval was obtained from the Pearl Institutional Review Board.
- The DSP methodology has been previously described,^{2,3} validated,⁴ shown to be representative of the consulting population, and shown to be consistent over time.⁵
- Neurologists and epileptologists completed patient record forms for consecutively consulting PwE with PS.
- The same PwE were invited to voluntarily provide patient self-completion forms.
- PwE were eligible for inclusion if they were ≥12 years of age, were receiving a stable regimen of antiseizure medications, and had experienced ≥1 PS in the prior 12 months.
- In this study, PS was defined as any seizure lasting ≥2 minutes and/or longer than normal.
- Non-PS were defined as the PwE's regular or normal seizures.
- SE was defined as any seizure lasting ≥5 minutes.
- SCs were defined as multiple seizures, with a distinct time of onset, with recovery between each seizure, occurring within 24 hours in adults, or 12 hours in children.
- Physicians provided data on demographics, seizure characteristics, disease burden, treatment including rescue medication, and HCRU.
- Data for the overall population have previously been presented.⁶
- Here, data are presented for the US subpopulation, and specific outcomes are presented for both PS and non-PS events.
- In the patient self-completion forms, PwE with PS were asked how much of an impact seizures have had on their life in the prior 3 months by providing a number from:
 - 0 'does not worry me at all' to 10 'causes me to worry all the time' regarding worrying about when the next seizure will occur, and
 - 0 'no impact' to 10 'most severe impact' for physical health, personal/home life, and mental health.

Results

DEMOGRAPHICS

- In the US subpopulation, 55 neurologists and 7 epileptologists completed patient record forms for 545 PwE experiencing PS in the prior 12 months.

Demographics

	ALL US PwE WITH PS (N=545)
Age, mean (SD), years	40.3 (15.56)
Age, median (Q1, Q3), years	39.0 (29.0, 50.0)
Male, n (%)	301 (55)
BMI, mean (SD), kg/m ²	25.7 (4.00)

BMI, body mass index; PS, prolonged seizures; PwE, people living with an epilepsy; Q1, 25th percentile; Q3, 75th percentile.

- 50.5% of PwE were in full- or part-time employment.
- Of PwE who were working part-time, retired, unemployed, or on long-term sick leave (n=200), this was due to PS in 34% of cases.

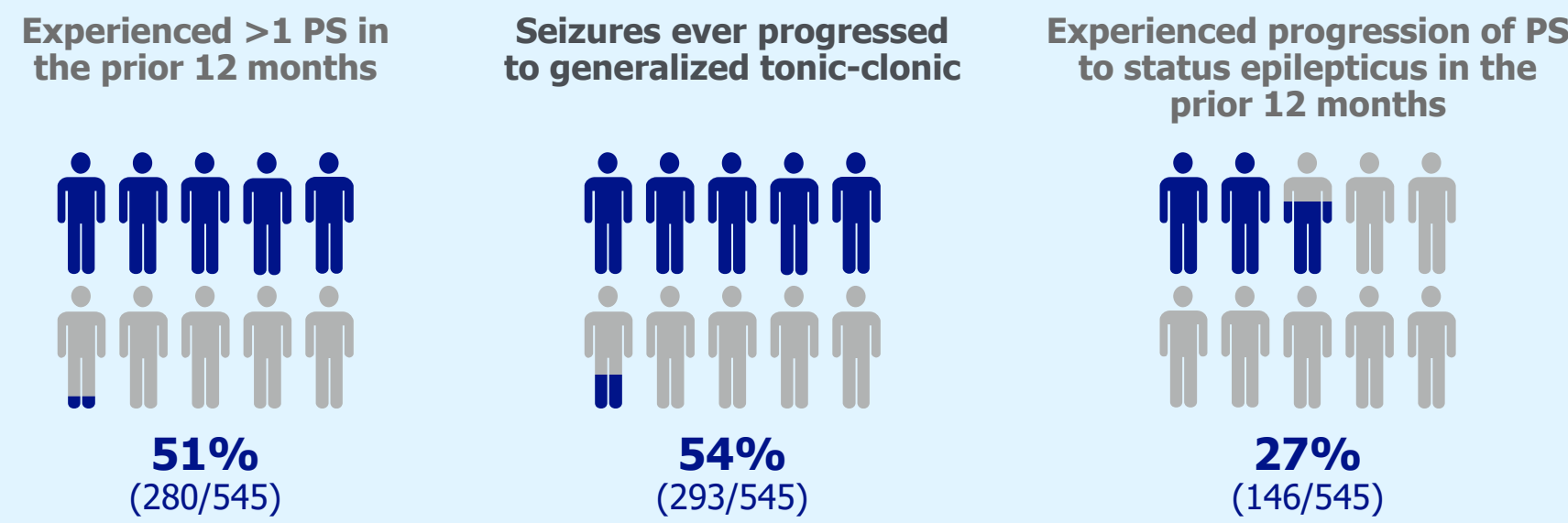
Overview

QUESTION

What are the characteristics, treatment patterns, and healthcare resource utilization among people living with an epilepsy (PwE) who experience prolonged seizures (PS) in the United States?

RESULTS

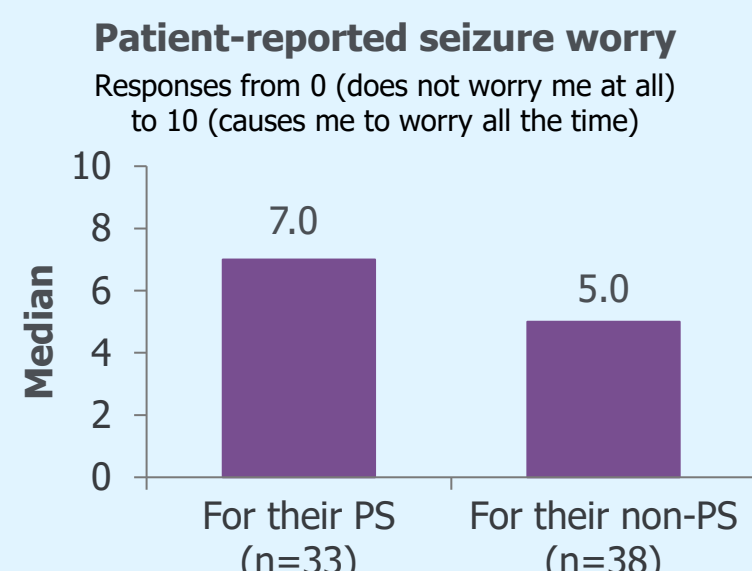
Seizure characteristics for PwE with PS (N=545)



INVESTIGATION

Data for the US subpopulation were drawn from Adelphi's PS Disease Specific Programme™, a real-world, point-in-time survey. 55 neurologists and 7 epileptologists completed patient record forms for 545 PwE experiencing PS in the prior 12 months.

Burden of living with PS



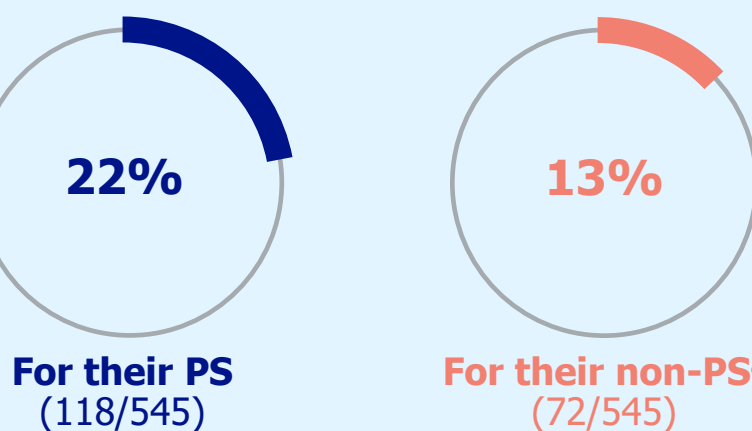
Seizure action plan (SAP)

PwE with PS who have a seizure action plan for their PS



Healthcare resource utilization (HCRU)

PwE with PS who required emergency services in the prior 12 months



CONCLUSIONS

Many PwE who experienced PS in the United States had experienced progression of their seizures to generalized tonic-clonic seizures and/or status epilepticus. PwE who experienced ≥1 PS were more likely to require hospitalization, emergency services, and emergency room and intensive care unit admissions for their PS than for their non-PS. These results highlight the need for better options for treating PS to prevent seizure progression to more severe states, reducing the burden on both PwE experiencing PS and their caregivers.

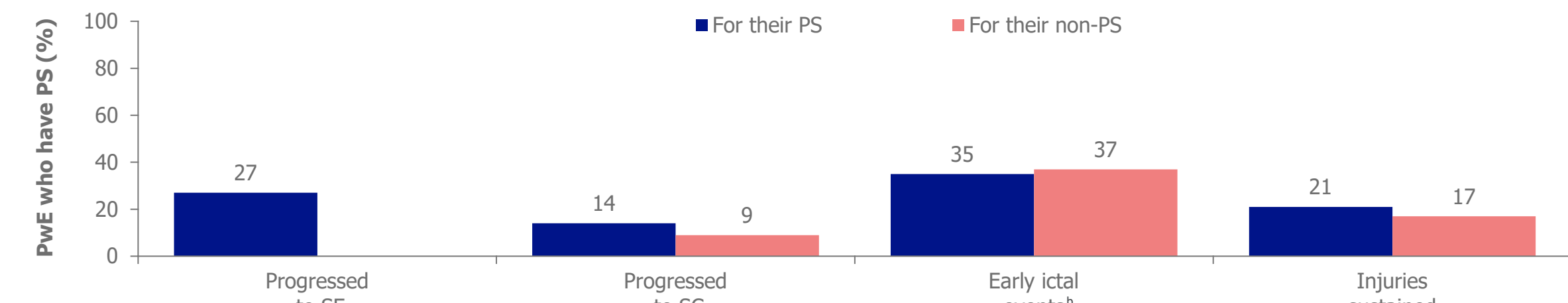
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SEIZURE CHARACTERISTICS

- 51% of PwE with PS had experienced >1 PS in the prior 12 months.
- 54% of PwE with PS had ever experienced progression of their seizures to generalized tonic-clonic seizures, 24% had ever experienced SCs, and 39% (n=192/497) had ever experienced progression of their seizures to SE.

Seizure characteristics in the prior 12 months^a (N=545)



^aPwE with PS who experienced an outcome in relation to their PS or non-PS events in the prior 12 months; ^bAuras/warning signs experienced before a seizure. PS, prolonged seizures; PwE, people living with an epilepsy; SC, seizure cluster; SE, status epilepticus.

Typical seizure details

	ALL US PwE WITH PS (N=545)	
	SEIZURE TYPES EVER EXPERIENCED, ^a n (%)	TYPICAL SEIZURE DURATION, MEDIAN (Q1, Q3), MINUTES
Focal to bilateral tonic-clonic (<i>partial evolving to secondarily generalized</i>)	158 (29)	2.0 (1.0, 4.0) ^b
Typical absence	157 (29)	1.0 (0.5, 2.0) ^c
Focal impaired consciousness (<i>complex partial</i>)	155 (28)	1.0 (0.5, 3.0) ^d
Primary generalized tonic-clonic	144 (26)	2.0 (1.0, 4.0) ^e
Focal preserved consciousness (<i>simple partial</i>)	66 (12)	1.1 (1.0, 2.0) ^f
Atypical absence	62 (11)	0.8 (0.5, 2.2) ^f
Myoclonic	57 (10)	2.0 (0.2, 3.0) ^g

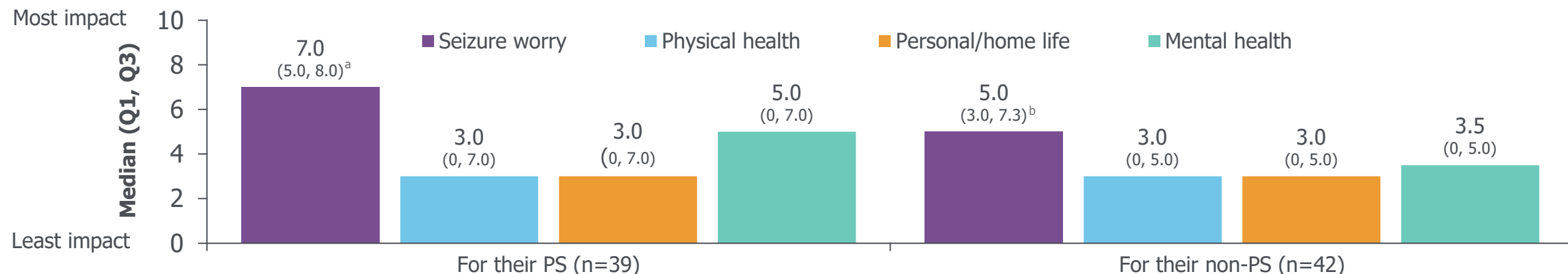
^aPatients could have had >1 response. Seizure types are listed per the ILAE 2025 classification^h with the seizure types per ILAE 1981ⁱ provided in parentheses; ^bn=155; ^cn=154; ^dn=152; ^en=134; ^fn=62; ^gn=52. ILAE, International League Against Epilepsy; PS, prolonged seizures; PwE, people living with an epilepsy; Q1, 25th percentile; Q3, 75th percentile.

- The median (25th percentile, 75th percentile) typical duration across all seizure types was 1.5 (0.8, 3.0) minutes (n=526).

BURDEN OF LIVING WITH PS

- Overall, 23% of PwE with PS had someone responsible for their daily needs.
- Of PwE with PS who had someone responsible for their daily needs (n=124), care was most commonly received from their parents (48%), professional caregiver(s) (31%), and partner/spouse (28%).

Patient-reported impact of PS and non-PS in the prior 3 months



Outcomes were assessed based on the impact that PS and non-PS events had over the prior 3 months; ^an=33; ^bn=38. PS, prolonged seizures; PwE, people living with an epilepsy; Q1, 25th percentile; Q3, 75th percentile.

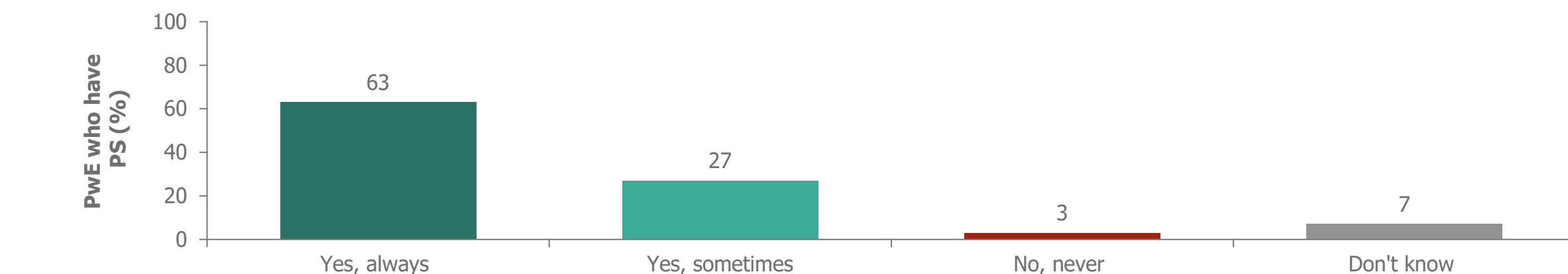
TREATMENT PATTERNS

- 70% of PwE with PS were currently prescribed any rescue medication.
- Of those prescribed rescue medication (n=379), oral benzodiazepines were the most prescribed rescue medication (37%), followed by intranasal midazolam (32%), and intranasal diazepam (27%).
- Rectal diazepam (7%) was less commonly prescribed.

SEIZURE ACTION PLANS

- 67% of PwE with PS had seizure action plans for taking their rescue medication in the event of a PS.

PwE who followed their seizure action plan^a (n=341)



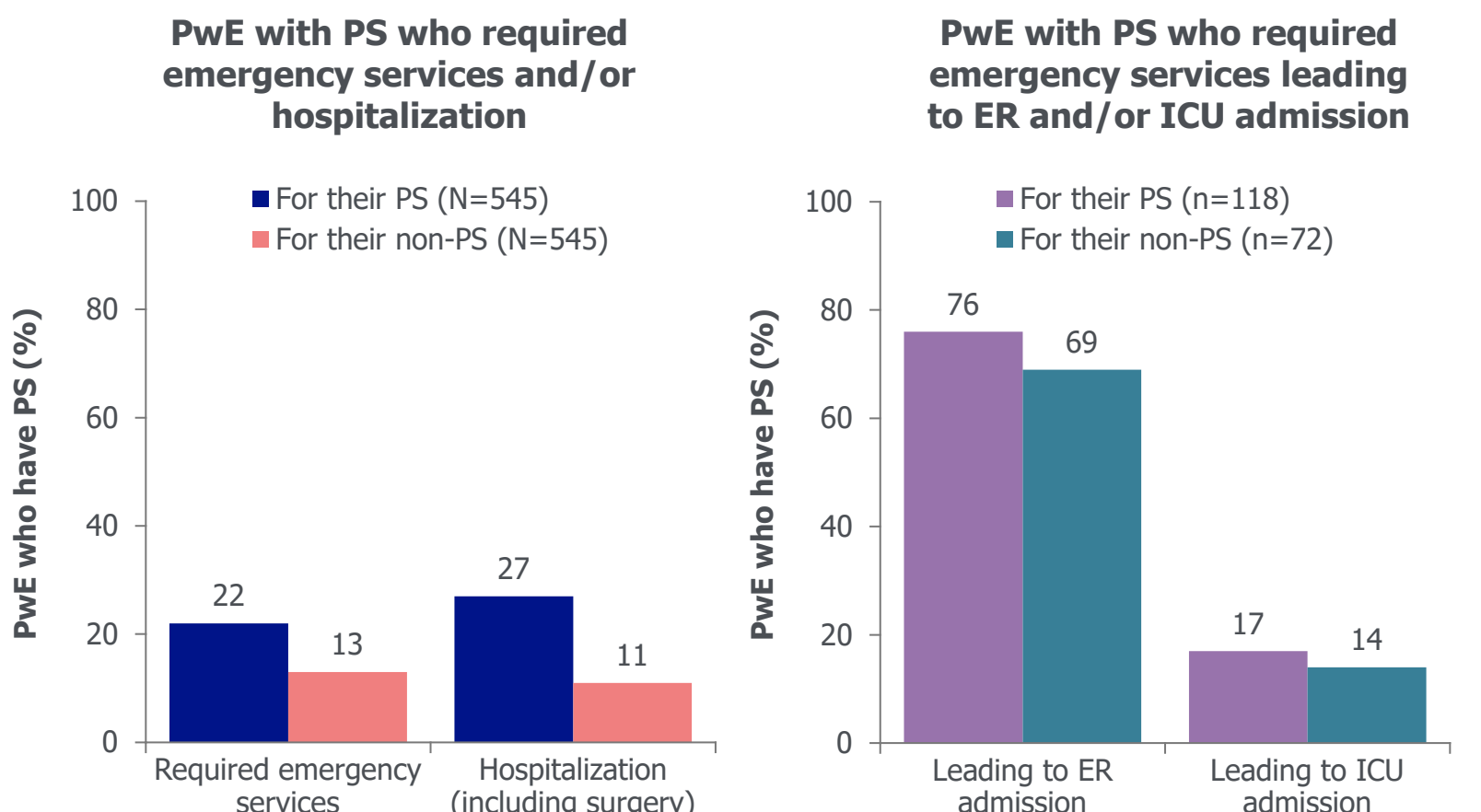
^aWhen physicians were asked if the PwE followed their seizure action plan for their PS. PS, prolonged seizures; PwE, people living with an epilepsy.

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HCRU

Emergency callouts and/or hospitalization in the prior 12 months^a



PwE with PS who experienced an outcome in relation to their PS or non-PS events in the prior 12 months; ^aHCRU data differ from data presented in accepted abstract; presented HCRU results include data for PwE with PS who required emergency services and/or hospitalization calculated out of all US PwE with PS (N=545), and PwE with PS who required emergency services leading to ER and/or ICU admission. ER, emergency room; HCRU, healthcare resource utilization; ICU, intensive care unit; PS, prolonged seizures; PwE, people living with an epilepsy.

Conclusions

- Many PwE who experienced PS in the United States had experienced progression of their seizures to generalized tonic-clonic seizures and/or SE.
- PwE who experienced ≥1 PS were more likely to require hospitalization, emergency services, and emergency room and intensive care unit admissions for their PS than their non-PS.
- PS have a subsequent impact on seizure worry among some PwE with PS.
- Approximately two-thirds of PwE with PS in the United States had a seizure action plan for PS; when physicians were asked if the PwE followed their seizure action plan for their PS, 63% responded 'yes, always'.
- These results highlight the need for better options for treating PS to prevent seizure progression to more severe states, reducing the burden on both PwE experiencing PS and their caregivers.

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