Poster P054

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

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Overview

QUESTION

What are the patient characteristics, treatment usage, and healthcare resource utilisation (HCRU) among patients with epilepsy with prolonged seizures (PS)?

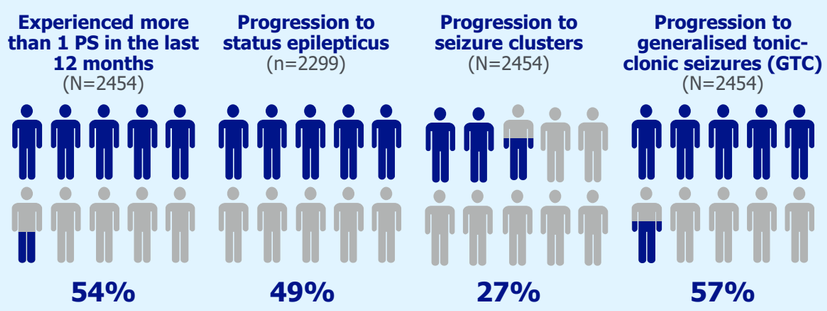
INVESTIGATION

Data were drawn from Adelphi's PS Disease Specific Programme™ (DSP), a real-world, point-in-time survey. Neurologists/epileptologists/internal medicine specialists (IMs) completed patient record forms for PwE with PS. Patients were invited to voluntarily complete patient self-completion forms.

RESULTS

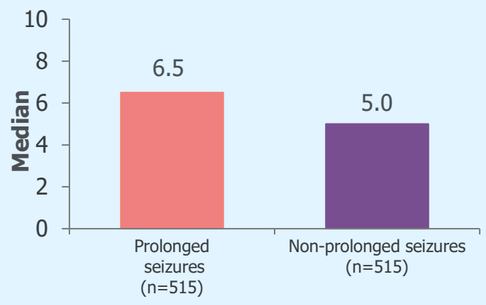
Seizure characteristics

Patients who have ever experienced seizure progression



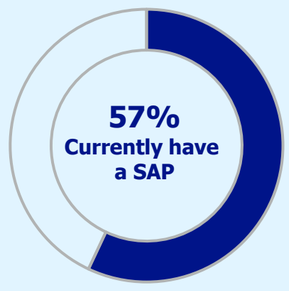
Burden of living with PS

Patient-reported seizure worry
(0 "does not worry me at all" to 10 "causes me worry all the time")



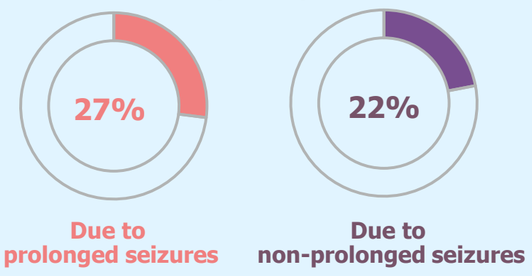
Seizure Action Plan (SAP)

Patient's SAP status (N=2454)



HCRU

Patients who required emergency services in the prior 12 months (N=2454)



CONCLUSIONS

PwE experiencing PS report high levels of burden from their PS, with the highest burden being seizure worry. Patients frequently encounter progression to SE, GTC seizures and/or SC, leading to injuries, emergency care, and hospital/ER/ICU admissions, despite best practice. More effective treatment options for PS are needed to minimise seizure progression and reduce disease burden.

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Background

- Prolonged seizures (PS), which may progress to status epilepticus (SE), are experienced by some people with epilepsy (PwE).
- There is currently no widely agreed definition for PS, but various definitions have been proposed.
- Recently, expert consensus recommendations have proposed definitions of 2 minutes for prolonged absence seizures and the convulsive phase of bilateral tonic-clonic seizures, and 5 minutes for prolonged focal seizures, suggesting that a consensus is emerging to define PS as shorter than status epilepticus.[1]
- However, despite the development of recent consensus definitions, the patient population of PS remains not well characterised.

Objective

- To describe patient characteristics, treatment usage, healthcare resource utilisation (HCRU) and overall disease burden, including work impairment and seizure worry, among PwE with PS.

Methods

- Data were drawn from Adelphi's PS Disease Specific Programme™ (DSP), a real-world, point-in-time survey conducted in United States, France, Germany, Italy, Spain, United Kingdom, Japan, and China between March 2023–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 consistent over time.[5]
- Neurologists/epileptologists/internal medicine specialists (IMs) completed patient record forms for consecutively consulting PwE with PS. The same patients were invited to voluntarily complete patient self-completion forms.
- Patients were eligible for inclusion if they:
  - Were ≥12 years old
  - Were receiving a stable regimen of anti-seizure medication
  - Had experienced ≥1 PS in prior 12 months.
- In this study, PS was defined as any seizure lasting ≥2 minutes and/or longer than normal ("non-PS"). SE was defined as any seizure(s) lasting ≥5 minutes. Seizure clusters (SC) 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 (RM), and HCRU.
- PwE with PS self-reported seizure worry using a 0-10 scale where 10 was "causes me to worry all the time" and 0 was "does not worry me at all".
- Data are presented for overall study population, and specific outcomes are presented for both PS and non-PS events.
- Analyses were descriptive, and the mean [standard deviation (SD)] was summarised for continuous variables. This was completed using Intelligence Reporter v7.5 (UNICOM Systems, Inc., Mission Hills, CA, USA).

Results

- Overall, 251 neurologists, 48 epileptologists, and 9 IMs completed patient record forms for 2454 PwE experiencing PS in the prior 12 months.

Table 1. Patient demographics

	ALL PATIENTS (N=2454)
Age	
Years, mean [SD]	38.8 [18.6]
Sex	
Male (n, %)	1382 (56%)
Female (n, %)	1068 (44%)
Intersex[a] (n, %)	4 (<1%)
BMI[b], kg/m²	
Mean [SD]	24.0 [3.82]

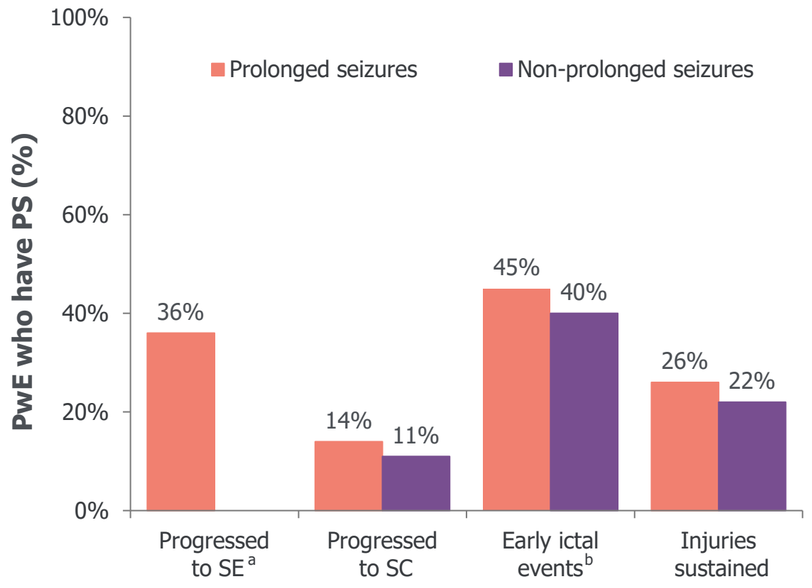
[a]Low base size; [b]Five patient values removed due to anomalously high BMIs >50.

- 37% of patients were in full or part-time employment. Of patients who were working part time/retired/unemployed/on long-term sick leave (n=992), this was due to PS in 34% of cases.

SEIZURE CHARACTERISTICS

- 49% of patients had ever experienced SE, and 27% had ever experienced SC.
- 54% of patients had experienced more than 1 PS in the prior 12 months.
- Prior 12-month reporting of seizure-linked events among patients is presented below (Figure 1).

Figure 1. Seizure characteristics in the prior 12 months



People with epilepsy with prolonged seizures who experienced an outcome in relation to their prolonged or non-prolonged seizure events in the prior 12 months (N=2454). [a]n=2299; [b]Auras/warning signs experienced before a seizure.

- With regards to seizures ever experienced, the most common seizure type experienced by patients was a primary generalised tonic-clonic seizure (36%). The median (IQR) typical duration across all seizure types was 2.0 (1.0, 3.0) minutes.

Table 2. Typical seizure details

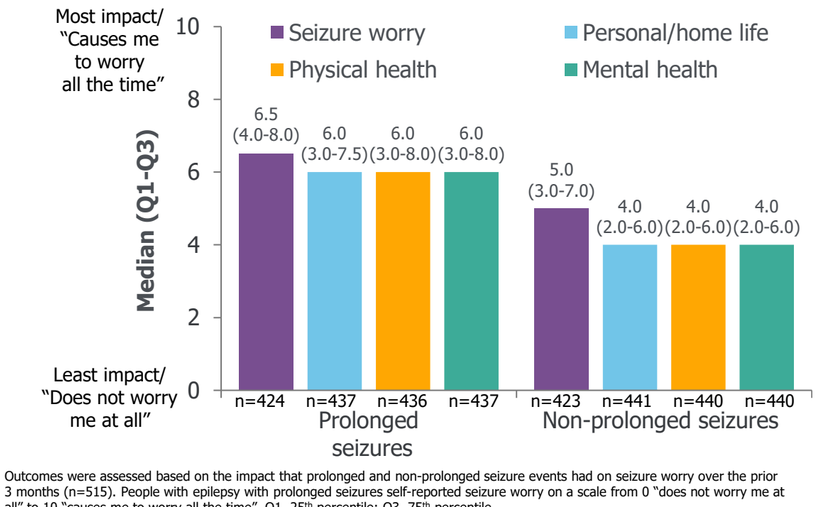
	ALL PATIENTS (N=2454)	
	SEIZURE TYPES EVER EXPERIENCED, n (%)	TYPICAL SEIZURE DURATION (MINUTES), MEDIAN [Q1, Q3]
Primary generalised tonic-clonic	877 (36)	2.0 [1.0, 4.0]
Focal to bilateral tonic-clonic	643 (26)	2.0 [1.0, 4.0]
Focal onset impaired awareness (complex partial)	630 (26)	2.0 [1.0, 4.0]
Typical absence	577 (24)	1.0 [0.3, 2.0]
Focal onset aware (simple partial)	462 (19)	2.0 [1.0, 3.0]
Myoclonic	385 (16)	1.0 [0.5, 3.0]
Atypical absence	285 (12)	1.0 [0.5, 3.0]
Other seizure type[a]	18 (1)	3.5 [0.8, 8.8]

[a]Low base size. Q1, 25th percentile; Q3, 75th percentile.

BURDEN OF LIVING WITH PS

- Based on non-PS and PS events in the last 3 months, patients reported their level of worry about when the next seizure will occur, and the impact of non-PS and PS on personal/home life, physical health and mental health (Figure 2).

Figure 2. Patient-reported impact of PS and non-PS in the prior 3 months



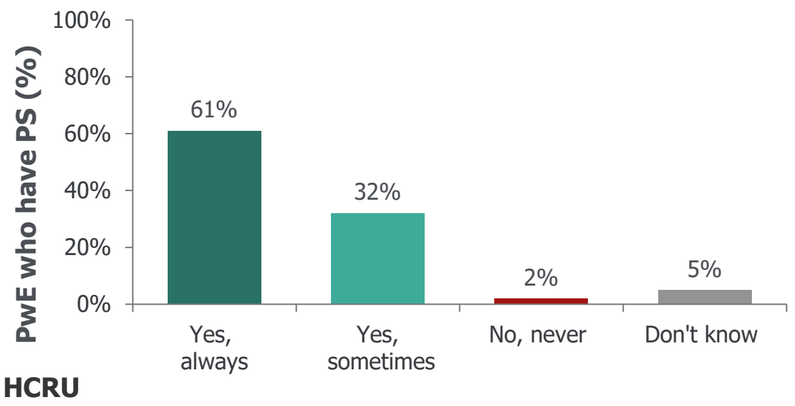
Outcomes were assessed based on the impact that prolonged and non-prolonged seizure events had on seizure worry over the prior 3 months (n=515). People with epilepsy with prolonged seizures self-reported seizure worry on a scale from 0 "does not worry me at all" to 10 "causes me to worry all the time". Q1, 25th percentile; Q3, 75th percentile.

- 41% of patients required caregiver support. Of patients who required caregiver support (n=1010), care was most commonly received from their parents (53%), partner/spouse (34%), and professional caregiver(s) (14%).

TREATMENT USAGE

- 60% of PwE with PS were prescribed RM.
- Of those prescribed RM (n=1471), 42% were prescribed oral benzodiazepines. Other RMs prescribed to patients included buccal midazolam (25%), intranasal midazolam (14%), intranasal diazepam (11%), rectal diazepam (9%), and other RM (1%).
- 57% of patients had seizure action plans for taking their RM in the event of a PS.

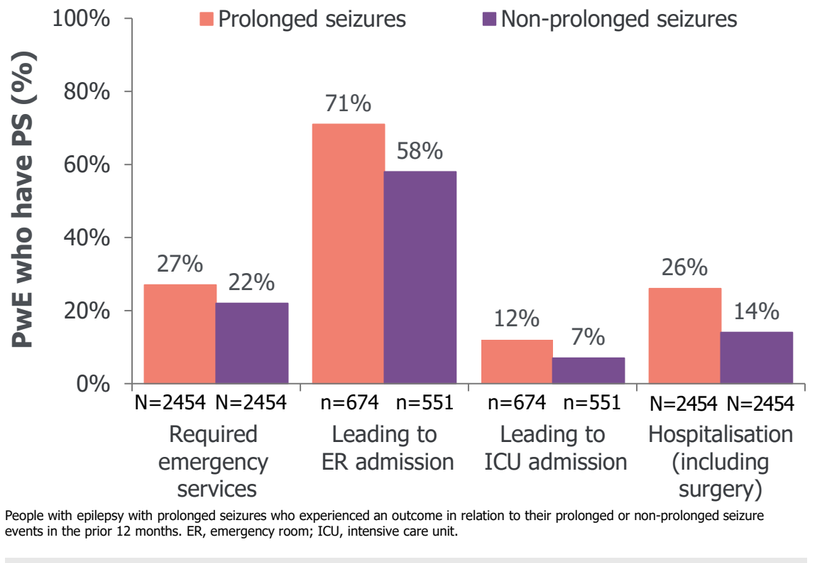
Figure 3. Do patients follow their seizure action plan?



HCRU

- Prior 12-month reporting of HCRU events among patients is presented below (Figure 4).

Figure 4. Emergency callouts and hospitalisation in the prior 12 months



People with epilepsy with prolonged seizures who experienced an outcome in relation to their prolonged or non-prolonged seizure events in the prior 12 months. ER, emergency room; ICU, intensive care unit.

Conclusions

- PwE reported a high level of seizure burden, with seizures frequently causing worry and impacting wellbeing. Patients regularly encounter progression to SE and/or SC, leading to injuries, emergency care, and hospital/ER/ICU admissions, despite best practice.
- This highlights the need for more effective treatment options for PS to minimise seizure progression to more severe states, ultimately reducing the burden on both PwE experiencing PS and their caregivers.

References

1. Pina-Garza J, et al. *Epileptic Disord* 2024;26(4):484-497.
2. Anderson P, et al. *Curr Med Res Opin* 2008;24:3063–3072.
3. Anderson P, et al. *Curr Med Res Opin* 2023;39:1707–1715.
4. Babineaux SM, et al. *BMJ Open* 2016;6:e010352.
5. Higgins V, et al. *Diabetes Metab Syndr Obes* 2016;9:371–380.

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