

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

Eugen Trinka^{1,3}
 Matthew C Walker⁴
 Reetta Kääläinen⁵
 Sheryl R Haut⁶
 John Stern⁷
 Lawrence J Hirsch⁸
 Alexander Gillespie⁹
 Laura LeBrocq¹⁰
 Cédric Laloyaux¹⁰
 Olaf Radunz¹¹
 J Claire Wilson¹²

¹ Department of Neurology, Neurocritical Care and Neurorehabilitation, Member of European Research Network CARE, Centre for Cognitive Neuroscience, Christian Doppler University Hospital, Paracelsus Medical University, Salzburg, Austria
² Neuroscience Institute, Centre for Cognitive Neuroscience, Christian Doppler University Hospital, Paracelsus Medical University, Salzburg, Austria
³ Institute for Health Services and Health Policy, University of Health Technology Assessment, University for Health Sciences, Medical Informatics and Technology, Hall in Tirol, Austria
⁴ UCL Queen Square Institute of Neurology, Department of Clinical & Experimental Epilepsy, UCL, London, UK
⁵ Department of Neurology, School of Medicine, University of Eastern Finland and Kuopio Epilepsy Centre, Member of European Reference Network EpICARE, Kuopio, Finland
⁶ Montefiore Medical Center, Albert Einstein Center, Albert Einstein College of Medicine, NY, USA
⁷ Department of Neurology, University of California, Los Angeles, Los Angeles, CA, USA
⁸ Comprehensive Epilepsy Center, Department of Neurology, Yale University, New Haven, CT, USA
⁹ Adelphi Real World, Bollington, UK
¹⁰ UCB, Brussels, Belgium
¹¹ UCB, Monheim am Rhein, Germany
¹² UCB, Slough, UK

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.

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

