Healthcare Resource Use of Pediatric and Adult Patients With Seizures Associated With Dravet Syndrome, Lennox-Gastaut Syndrome, or Tuberous Sclerosis Complex in Japan

RWD 266

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Introduction

- Dravet syndrome (DS), Lennox-Gastaut syndrome (LGS), and tuberous sclerosis complex (TSC)-associated epilepsy are severe, treatment-resistant, and rare epilepsy syndromes that begin in early childhood and persist with lifelong seizures. Patients affected by these disorders exhibit significant intellectual and physical disabilities requiring long-term care[1–4]
- The complex nature of these disorders, including the severity of seizures, contributes to reduced health-related quality of life, increased healthcare resource utilization (HCRU), and substantial burden on caregivers due to patients' dependence on them for daily life activities[1,4–7]
- Although DS, LGS, and TSC are associated with a broader disease burden, including intellectual and physical disabilities,[1–4] this study focused on the seizure-related burden, for which HCRU data in Japan remain limited

Objective

- To evaluate the HCRU of pediatric and adult patients experiencing seizures associated with DS, LGS, or TSC in Japan, based on insights from clinical expert interviews

Methods

- Clinicians experienced in treating patients with these conditions in Japan were recruited and interviewed in December 2024
- Interviews were blinded, lasted 60 minutes each, and were conducted via telephone and/or video conference
  - More interviews were conducted for TSC in order to cover patients with generalized or focal seizures with impairment
- The data collected represented physicians' perception of HCRU rather than patient-level data
- Health states were developed based on seizure frequency, which varied by the condition, and were deemed appropriate to capture meaningful differences in HCRU across a range of patients
- Results for each indication, stratified by pediatrics (2–17 years) and adults (≥18 years), were reviewed and summarized after interview completion

Conclusions

- A trend of **increasing HCRU was reported across all indications as seizure frequency increased**
- **HCRU was generally lower in adult patients** compared with pediatric patients, and in TSC patients with focal seizures with impairment compared with those with generalized seizures
- Study limitations include:
  - Data are limited to the opinion of only six clinical experts and are their subjective interpretation
  - Patient-level data were not collected
  - Seizure frequency alone may not correlate with visit frequency
  - Other factors such as seizure control and time since seizure onset may also have an impact, but these were not explored in the current study

Results

- Six clinical experts from Japan were interviewed (three pediatric neurologists and three neurologists)

Interviews conducted:
4 for DS, 4 for LGS, 6 for TSC

Table 1. Hospitalizations, outpatient visits, and rescue medication use in patients with seizures associated with DS

Health state	Hospital admissions (mean per year)		Length of stay per admission (mean, days)		Patients (%) in general ward (versus ICU)		Emergency room visits (mean per year)		Non-emergency room visits (mean per year)		Patients using rescue medications per year (%)		Number of rescue medication uses (mean per year)	
	Pediatrics	Adults	Pediatrics	Adults	Pediatrics	Adults	Pediatrics	Adults	Pediatrics	Adults	Pediatrics	Adults	Pediatrics	Adults
Seizure-free patients	0.0	0.0	n/a	n/a	n/a	n/a	0.0	0.0	6.0	4.0	0%	0%	n/a	n/a
≤8 seizures per month (but not seizure-free)	1.0	0.5	5.0	3.0	95%	95%	6.0	3.0	6.0	6.0	30%	20%	2.0	1.0
>8–≤25 seizures per month	3.0	1.5	5.0	3.0	95%	95%	12.0	6.0	12.0	12.0	60%	30%	3.0	1.0
>25 seizures per month	8.0	3.0	5.0	3.0	95%	95%	24.0	12.0	24.0	12.0	60%	30%	6.0	2.0

Hospitalizations and emergency room visits increased with seizure frequency in both age groups

Patients using rescue medication and number of rescue medication uses increased with seizure frequency in both age groups

In adults, the annual institutionalization[a] rate was 0% among seizure-free patients and 15% among patients experiencing any number of seizures

[a]Institutionalization is not common in Japan. Patients are often institutionalized only when caregivers become too elderly to provide care.
DS, Dravet syndrome; ICU, intensive care unit; n/a, not applicable.

Table 2. Hospitalizations, outpatient visits, and rescue medication use in patients with seizures associated with LGS

Health state	Hospital admissions (mean per year)		Length of stay per admission (mean, days)		Patients (%) in general ward (versus ICU)		Emergency room visits (mean per year)		Non-emergency room visits (mean per year)		Patients using rescue medications per year (%)		Number of rescue medication uses (mean per year)	
	Pediatrics	Adults	Pediatrics	Adults	Pediatrics	Adults	Pediatrics	Adults	Pediatrics	Adults	Pediatrics	Adults	Pediatrics	Adults
Seizure-free patients	0.0	0.0	n/a	n/a	n/a	n/a	0.0	0.0	6.0	4.0	0%	0%	n/a	n/a
≤45 seizures per month (but not seizure-free)	0.5	0.5	4.5	3.0	95%	95%	1.0	1.0	6.0	6.0	100%	100%	2.0	2.0
>45–≤110 seizures per month	1.3	1.3	4.5	3.0	95%	95%	2.5	2.5	12.0	12.0	100%	100%	5.0	5.0
>110 seizures per month	2.0	2.0	4.5	3.0	95%	95%	4.0	4.0	24.0	12.0	100%	100%	8.0	8.0

Hospitalizations and emergency room visits increased with seizure frequency in both age groups

All patients with seizures used rescue medications; number of rescue medication uses increased with seizure frequency in both age groups

In adults, the annual institutionalization[a] rate was 0% among seizure-free patients and 15% among patients experiencing any number of seizures

[a]Institutionalization is not common in Japan. Patients are often institutionalized only when caregivers become too elderly to provide care.
ICU, intensive care unit; LGS, Lennox-Gastaut syndrome; n/a, not applicable.

Table 3. Hospitalizations, outpatient visits, and rescue medication use in patients with seizures associated with TSC

Health state	Hospital admissions (mean per year)		Length of stay per admission (mean, days)		Hospital outpatient visits (mean per year)		ICU admissions (mean per year)		Emergency room visits (mean per year)		Physiotherapy outpatient visits (mean per year)		MRI scans (mean per year)		Number of rescue medication uses (mean per year)	
	Pediatrics	Adults	Pediatrics	Adults	Pediatrics	Adults	Pediatrics	Adults	Pediatrics	Adults	Pediatrics	Adults	Pediatrics	Adults	Pediatrics	Adults
Generalized seizures																
Seizure-free patients	0.7	0.7	0.0	0.0	4.0	4.0	0.1	0.1	0.6	0.5	0.7	0.3	0.4	0.3	0.0	0.0
≤2 seizures per week (but not seizure-free)	2.3	2.2	4.0	4.0	12.0	12.0	0.5	0.5	1.8	1.7	1.4	0.6	0.4	0.4	1.1	0.4
>2–≤7 seizures per week	5.1	6.0	4.0	4.0	12.0	12.0	1.1	1.7	3.3	3.6	2.4	0.6	0.5	0.7	4.0	2.6
>7 seizures per week	8.0	8.0	7.0	7.0	12.0	12.0	3.3	4.8	6.3	5.3	5.3	1.6	0.9	1.3	18.0	8.9
Focal seizures with impairment																
Seizure-free patients	0.0	0.0	n/a	n/a	1.4	1.0	0.0	0.0	0.4	0.3	0.7	0.3	0.3	0.3	0.0	0.0
≤2 seizures per week (but not seizure-free)	0.0	0.0	n/a	n/a	3.1	2.4	0.0	0.0	0.5	0.5	1.4	0.6	0.4	0.4	0.7	0.2
>2–≤7 seizures per week	0.5	0.5	4.0	4.0	8.0	8.0	0.0	0.0	1.0	1.0	2.4	0.6	0.5	0.6	2.5	1.6
>7 seizures per week	1.0	1.0	7.0	7.0	12.0	12.0	0.0	0.0	2.0	2.0	5.3	1.6	0.8	1.2	11.1	5.5

HCRU, including annual hospitalizations, outpatient visits, ICU admissions, emergency room visits, and rescue medication use, were slightly lower in patients with TSC experiencing focal seizures with impairment versus generalized seizures for both pediatric and adult patients

ICU, intensive care unit; MRI, magnetic resonance imaging; n/a, not applicable; TSC, tuberous sclerosis complex.

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