Patient and Caregiver Preferences for Acute Seizure Medications: A Quantitative Survey

Cedric Laloyaux[1]
Tommi Tervonen[2]
Vicente Villanueva[3]
Joseph Sirven[4]
Alison Kukla[5]
Cecilia Jimenez-Moreno[6]
Kerrie-Anne Ho[7]

1. UCB, Brussels, Belgium
2. Kielo Research, Zug, Switzerland
3. Universitario y Politécnico La Fe, Valencia, Spain, member of ERN EPICARE
4. Mayo Clinic, Jacksonville, FL, USA
5. Partners Against Mortality in Epilepsy, Chicago, IL, USA
6. Kielo Research, York, UK
7. UCB, Slough, UK

Background

- Rapid and Early Seizure Termination (REST) is a new treatment paradigm potentially involving future fast-acting medications used very early in an ongoing seizure to prevent it from becoming prolonged or progressing in severity, whereas acute cluster treatments (rescue medications) are given to prevent the next or further seizures in a cluster.[1]

Objective

- To explore the preferences of people with epilepsy or an epilepsy syndrome (PwE) and their caregivers (CGs) for attributes of acute (on-demand) seizure medications for prolonged seizures (PS), using preference elicitation exercises.

Methods

- This was a preference survey of adult (aged ≥18 years) PwE who had experienced ≥1 PS in the past 12 months, and adult CGs of adolescent (aged 12-17 years) or adult PwE who had experienced ≥1 PS in the past 12 months. Participants were recruited from France, Italy, Poland, Spain, the United Kingdom, and the United States (US).
  - PS were defined as generalized seizures of ≥2 minutes or focal seizures of ≥5 minutes.
- Participants completed a discrete choice experiment (DCE) involving a series of choice tasks in which they selected between two hypothetical treatment options comprising five attributes (mode of administration, treatment time window, time to stop the seizure, probability to stop the seizure within the treatment time frame, and no seizure recurrence for the next 12 hours); and an exercise assessing their willingness to wait when experiencing a seizure or an aura before deciding to administer an acute seizure medication.
- Descriptive analyses were conducted on participant characteristics and results of the willingness to wait exercise.
- DCE results were analyzed using multinomial logit (MNL) models, including a linear-coded MNL model for the overall analysis and interacted MNL models for subgroup analyses.
  - Relative attribute importance (RAI) was calculated using the full-sample linear-coded MNL model.

Results

PARTICIPANT CHARACTERISTICS

- A total of 526 candidates were screened. Of these, 48 failed screening and 478 proceeded to open the survey. Among the 478 participants, 104 withdrew and 374 completed the survey and were included in the analysis.

Characteristics of PwE and CG participants

	OVERALL (N=374)	ADULT PwE (n=135)	CG OF ADOLESCENT (n=119)	CG OF ADULT (n=120)
Country, n (%)				
United States	148 (40)	65 (48)	42 (35)	41 (34)
Italy	69 (18)	24 (18)	23 (19)	22 (18)
Poland	46 (12)	14 (10)	16 (13)	16 (13)
France	40 (11)	10 (7.4)	14 (12)	16 (13)
United Kingdom	40 (11)	10 (7.4)	14 (12)	16 (13)
Spain	31 (8.3)	12 (8.9)	10 (8.4)	9 (7.5)
Age, median (Q1, Q3), years	45 (35, 54)	38 (28, 52)	45 (39, 50)	49 (40, 56)
Female, n (%)	242 (65)	73 (54)	82 (69)	87 (73)

CG, caregiver; PwE, people with epilepsy or an epilepsy syndrome; Q1, 25th percentile; Q3, 75th percentile.

Characteristics of CG participants

	OVERALL (n=239)	CG OF ADOLESCENT (n=119)	CG OF ADULT (n=120)
Age of person with epilepsy, median (Q1, Q3), years	18 (14, 40)	14 (13, 16)	40 (24, 59)
Current highest level of caregiving responsibility, n (%)			
Sporadic care (eg, accompaniment to physician's appointments, light errands, sporadic in-house or telephone check-ins)	33 (14)	11 (9.2)	22 (18)
Household care (eg, more frequent monitoring of symptoms and medications, support with finances and/or household tasks, coordinating the patient's care plan)	83 (35)	38 (32)	45 (38)
Personal care (eg, household help, additional support with tasks of personal care like dressing up and hygiene, providing acute care to manage symptoms on the day-to-day)	64 (27)	30 (25)	34 (28)
Advanced care (when the CG completes all day-to-day activities)	59 (25)	40 (34)	19 (16)

CG, caregiver; Q1, 25th percentile; Q3, 75th percentile.

Seizure experience: most common seizure type[a]

n (%)	OVERALL (N=374)	ADULT PwE (n=135)	CG OF ADOLESCENT (n=119)	CG OF ADULT (n=120)
Focal seizures/without loss of awareness	91 (24)	34 (25)	31 (26)	26 (22)
Focal seizures/with loss of awareness	91 (24)	32 (24)	34 (29)	25 (21)
Generalized or bilateral seizures/ tonic-clonic	173 (46)	52 (39)	56 (47)	65 (54)
Generalized or bilateral seizures/ non-motor	72 (19)	33 (24)	20 (17)	19 (16)
Unknown offset/present visible physical movement, jerks, or body stiffness	36 (9.6)	13 (9.6)	11 (9.2)	12 (10)
Unknown offset/without any visible movements of the body or as an absence	12 (3.2)	6 (4.4)	4 (3.4)	2 (1.7)

[a]This study was completed before the 2025 updated seizure classification by the International League Against Epilepsy[2] was published. CG, caregiver; PwE, people with epilepsy or an epilepsy syndrome.

Overview

QUESTION

What are the preferences of people with epilepsy or an epilepsy syndrome (PwE) and their caregivers (CGs) for attributes of acute (on-demand) seizure medications for prolonged seizures (PS)?

INVESTIGATION

Preference survey of adult (aged ≥18 years) PwE who had experienced ≥1 PS in the past 12 months, and adult CGs of adolescent (aged 12-17 years) or adult PwE who had experienced ≥1 PS in the past 12 months. PS were defined as generalized seizures of ≥2 minutes or focal seizures of ≥5 minutes. Participants were recruited from France, Italy, Poland, Spain, the United Kingdom, and the United States (N=374).

RESULTS

Participants' preferences regarding different attributes of acute seizure medications (discrete choice experiment [DCE])

- All attributes examined (time to stop the seizure, mode of administration, treatment time window, probability to stop the seizure within the time frame, and no seizure recurrence for the next 12 hours) significantly influenced treatment preferences.

Time to stop the seizure

Participants preferred to stop the seizure within 1 or 2 minutes

Mode of administration[a]

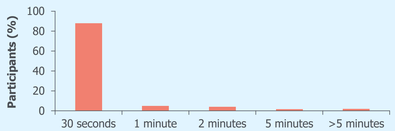
Participants preferred nasal sprays and single-use inhalers

Treatment time window[b]

Participants preferred administering treatment at the first symptoms or once the seizure has become prolonged

[a]Images: Flaticon.com. [b]Markers indicate the following time points: at the first symptoms of seizure, once the seizure has become prolonged, and once a seizure has progressed to status epilepticus.

Participants' willingness to wait when experiencing a seizure before deciding to administer an acute seizure medication



CONCLUSIONS

Discrete choice experiment results showed that adult PwE and CGs of adult and adolescent PwE value fast-acting acute seizure medications (those that can stop a seizure within 1-2 minutes, the shortest times proposed). Participants preferred nasal sprays and single-use inhalers; rectal administration was least preferred. Participants also indicated a preference for administering these treatments early in the seizure, either at the first symptoms or once the seizure has become prolonged. In the willingness to wait exercise, most participants would not wait longer than 30 seconds (the shortest time proposed) before administering an acute seizure medication. The importance of the treatment attributes suggests an unmet need for a fast-acting medication with an appropriate mode of administration, as well as a need to reassess the recommendation to wait for several minutes before administering treatment for PS.

For a copy of the poster, scan:

Frequency and duration of seizures during the past 12 months

n (%)	OVERALL (N=374)	ADULT PwE (n=135)	CG OF ADOLESCENT (n=119)	CG OF ADULT (n=120)
Average number of seizures per month during the past 12 months				
<3	86 (23)	34 (25)	23 (19)	29 (24)
3-5	193 (52)	69 (51)	66 (55)	58 (48)
6-10	55 (15)	14 (10)	21 (18)	20 (17)
11-20	18 (4.8)	8 (5.9)	3 (2.5)	7 (5.8)
>20	22 (5.9)	10 (7.4)	6 (5.0)	6 (5.0)
Average duration of the most common type of seizure experienced during the past 12 months				
<1 minutes	27 (7.2)	16 (12)	9 (7.6)	2 (1.7)
1-2 minutes	86 (23)	29 (21)	27 (23)	30 (25)
2-4 minutes	128 (34)	46 (34)	43 (36)	39 (33)
4-5 minutes	65 (17)	20 (15)	23 (19)	22 (18)
>5 minutes	68 (18)	24 (18)	17 (14)	27 (23)

CG, caregiver; PwE, people with epilepsy or an epilepsy syndrome.

Current acute (on-demand) medications to treat PS

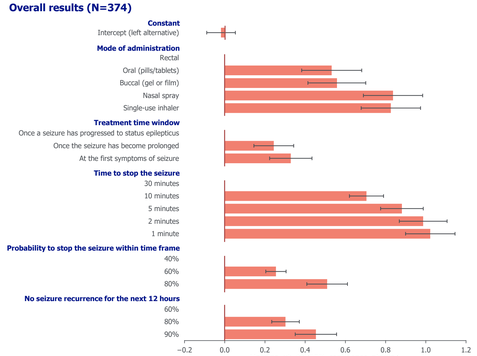
n (%)	OVERALL (N=374)	ADULT PwE (n=135)	CG OF ADOLESCENT (n=119)	CG OF ADULT (n=120)
Oral	212 (57)	72 (53)	65 (55)	75 (63)
Rectal	72 (19)	18 (13)	33 (28)	21 (18)
Intranasal spray[a]	39 (10)	20 (15)	8 (6.7)	11 (9.2)
Intravenous or intramuscular injection	60 (16)	21 (16)	19 (16)	20 (17)
Buccal[b]	59 (16)	15 (11)	24 (20)	20 (17)
Not using benzodiazepines as acute ('on-demand') medication to treat PS	27 (7.2)	16 (12)	4 (3.4)	7 (5.8)

[a]Intranasal spray option was only available to participants in the United States; [b]Buccal option was only available to participants in Europe. CG, caregiver; PS, prolonged seizure; PwE, people with epilepsy or an epilepsy syndrome.

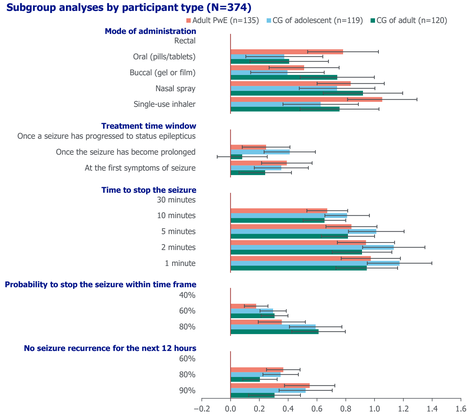
PARTICIPANTS' TREATMENT PREFERENCES

- All attributes significantly influenced participants' treatment preferences (all p<0.001).
- The most important was time to stop the seizure (RAI=32.4%) and mode of administration (RAI=26.6%), then probability to stop the seizure within the time frame (RAI=16.2%), no seizure recurrence for the next 12 hours (RAI=14.4%), and finally treatment time window (RAI=10.4%).
- Participants preferred acute seizure medications that can stop a seizure within 1-2 minutes.
- Participants preferred nasal sprays and single-use inhalers; rectal administration was least preferred.
- Participants also preferred administering acute seizure medications early in the seizure, either at the first symptoms or once the seizure has become prolonged.

Overall results (N=374)



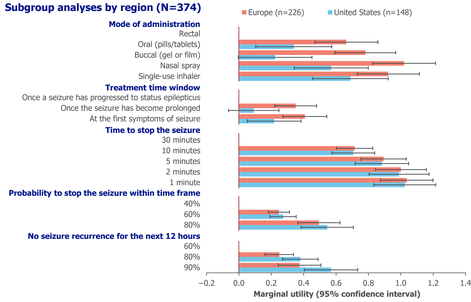
Subgroup analyses by participant type (N=374)



CG, caregiver; PwE, people with epilepsy or an epilepsy syndrome.

- Single-use inhaler was valued more by adult PwE than by CGs of adolescents (p<0.05).
- Improving the chance of stopping the seizure within the provided time frame was valued more by CGs of adults and CGs of adolescents than by adult PwE (p<0.05 and p=0.06, respectively).
- Improving the chance to avoid seizure recurrence for the next 12 hours was more important to adult PwE than to CGs of adults (p=0.06).

Subgroup analyses by region (N=374)



- European participants valued oral, buccal, and nasal spray administration more than US participants (p<0.05, p<0.001, and p<0.01, respectively).
- Treatment time window was more important to European participants, who wanted to treat seizures earlier than US participants (p<0.05 for 'once the seizure has become prolonged' and p=0.08 for 'at the first symptoms of seizure').
- Improving the chance to avoid seizure recurrence for the next 12 hours was somewhat more important to US vs European participants (p=0.07).

Willingness to wait before deciding to administer an acute seizure medication

n (%)	OVERALL (N=374)	ADULT PwE (n=135)	CG OF ADOLESCENT (n=119)	CG OF ADULT (n=120)
30 seconds	328 (88)	125 (93)	97 (82)	106 (88)
1 minute	18 (4.8)	4 (3.0)	8 (6.7)	6 (5.0)
2 minutes	15 (4.0)	4 (3.0)	9 (7.6)	2 (1.7)
5 minutes	6 (1.6)	0 (0)	2 (1.7)	4 (3.3)
>5 minutes	7 (1.9)	2 (1.5)	3 (2.5)	2 (1.7)

CG, caregiver; PwE, people with epilepsy or an epilepsy syndrome.

Conclusions

- DCE results showed that adult PwE and CGs of adult and adolescent PwE value fast-acting acute seizure medications (those that can stop a seizure within 1-2 minutes, the shortest times proposed).
  - Participants preferred nasal sprays and single-use inhalers; rectal administration was least preferred.
  - Participants also indicated a preference for administering these treatments early in the seizure, either at the first symptoms or once the seizure has become prolonged.
  - In subgroup analyses:
    - Single-use inhaler was valued more by adult PwE than by CGs of adolescents
    - Improving the chance of stopping the seizure within the provided time frame was valued more by CGs of adults and CGs of adolescents than by adult PwE
    - Improving the chance to avoid seizure recurrence for the next 12 hours was more important to adult PwE than to CGs of adults.
- In the willingness to wait exercise, most participants would not wait longer than 30 seconds (the shortest time proposed) before administering an acute seizure medication.
- The importance of the treatment attributes suggests an unmet need for a fast-acting medication with an appropriate mode of administration, as well as a need to reassess the recommendation to wait for several minutes before administering treatment for PS.

References

1. Pina-Garza JE, et al. *Epileptic Disord* 2024;26(4):484-497.
2. Benicky S, et al. *Epilepsia* 2025;66(6):1804-1823.

UCB-sponsored. UCB was involved in the design of the study, the collection, analysis, and interpretation of data, and review of the poster. The authors thank the PwE and their CGs in addition to the investigators and their teams who contributed to this study. The authors acknowledge Tom Grant, PhD (UCB, Slough, UK) for managing the development of the poster, and Emily Chu, PhD (Envision Spark, an Envision Medical Communications agency, a part of Envision Pharma Group, Horsham, UK) for writing assistance, which was funded by UCB. Author contributions: C Laloyaux, T Tervonen, C Jimenez-Moreno, and K-A Ho designed the study. T Tervonen and C Jimenez-Moreno analyzed the data. All authors interpreted the data, critically reviewed the poster, and approved the final version for presentation. Author disclosures: C Laloyaux is an employee of UCB and has received stocks from his employment. T Tervonen and C Jimenez-Moreno are employees of Kielo Research, which received funds from UCB related to this study. T Tervonen owns stock in Kielo Research. V Villanueva has served as a consultant or on an advisory board for Arvelle Therapeutics, Bial, Eisai, Esteve, GW Pharmaceuticals, Novartis, and UCB; has received research grants from Bial, Eisai, and UCB; and has received speaker's honoraria from Bial, Eisai, Esteve, GW Pharmaceuticals, Novartis, and UCB. J Sirven has served as a consultant for Acorda Therapeutics, Neurelis, UCB, and Upsher-Smith. A Kukla receives salary support for consulting activities on behalf of The International Bureau for Epilepsy, a non-profit organization. She also provides paid support to the American Epilepsy Society in support of Partners Against Mortality in Epilepsy activities. She is a paid advisor for Neurelis Pharmaceuticals and UCB. She has also received travel support from the Epilepsy Alliance and Epilepsy Foundation. K-A Ho is an employee of UCB and has received stocks from her employment.

For a copy of this poster, use your smartphone to scan the QR code or contact UCB**Cares**®
Phone: +1-844-599-CARE (2273)
Email: UCBCares@ucb.com

American Epilepsy Society 79th Annual Meeting
Atlanta, GA, USA | December 5–9, 2025