

Patient and Caregiver Perceptions of Acute Seizure Medications and the Rapid and Early Seizure Termination (REST) Approach: Qualitative Interviews

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OVERVIEW

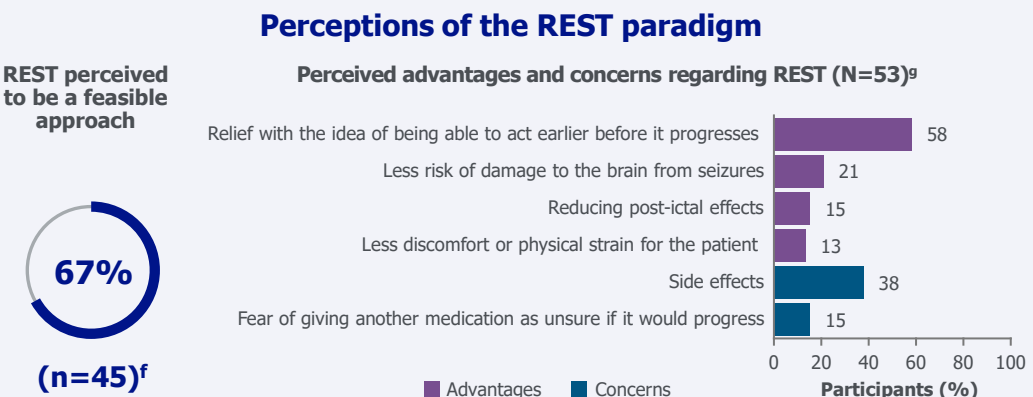
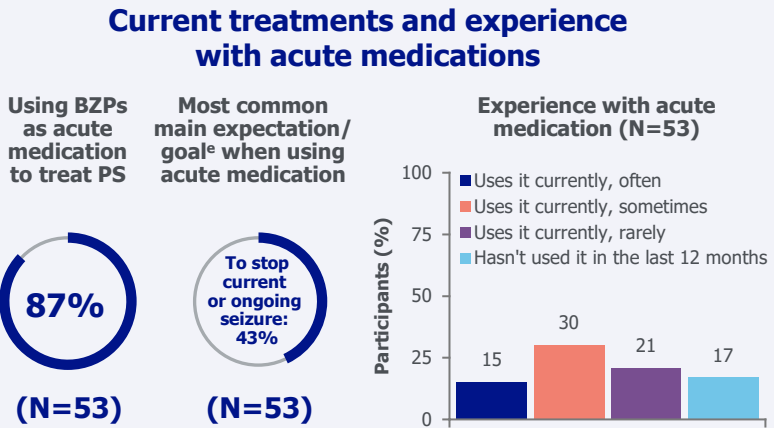
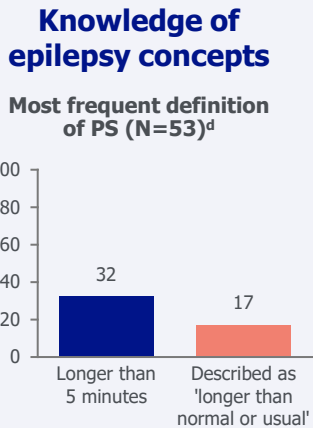
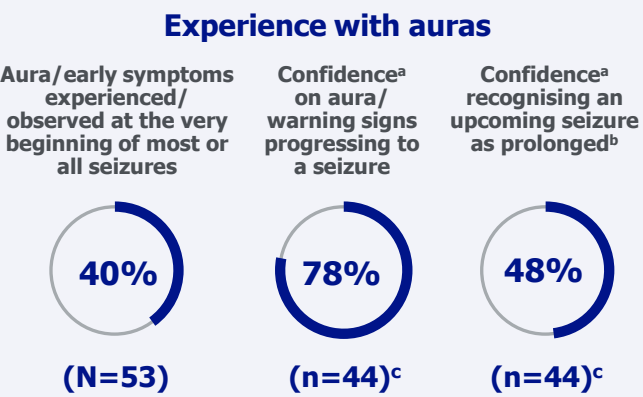
QUESTION

Among people with epilepsy (PwE) and caregivers of PwE, what is the experience of prolonged seizures (PS) and acute medications and the level of understanding and perception of the Rapid and Early Seizure Termination (REST) paradigm?

INVESTIGATION

Participants included PwE ≥18 years of age, with a diagnosis of epilepsy/epilepsy syndrome who had experienced ≥1 PS (≥2 minutes) in the prior 12 months and caregivers (≥18 years of age) of PwE (≥12 years of age). Participants took part in qualitative interviews regarding experiences with auras, epilepsy concepts, experience and unmet needs of acute medications, and perceptions of the REST paradigm.

RESULTS



^aExtremely confident, very confident, or confident; ^bFrom participants' experience with auras; ^cNine participants reported not experiencing any auras or warning signs; ^dMore than one definition could have been given; ^eMore than one expectation/goal could have been given; ^fOf 45 participants who were not treating seizures early; ^gMentioned by >10% of participants; >1 answer could have been given.

CONCLUSIONS

- Many participants reported they could confidently predict seizures based on auras.
- Most participants reported using or administering a benzodiazepine as an acute medication for PS.
- Most participants felt that REST is a feasible approach and suggested it could provide relief with being able to act earlier before seizures progress.
- REST could be a beneficial and fast-acting approach to prevent seizures becoming PS or progressing in severity.

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Background

- Rapid and Early Seizure Termination (REST) is essential to prevent seizures becoming prolonged seizures (PS) or progressing in severity.¹
- REST is a new management paradigm that encompasses the acute treatment of ongoing seizures, with the aim of being rapid (quick onset of action) and early (used as close to seizure onset as possible).¹
- However, among people with epilepsy (PwE) and caregivers, awareness of the REST paradigm and perceptions around acute (on-demand) medications are not well known.

Objective

- To understand the experience of PS and acute medications among PwE and caregivers of PwE and assess the understanding and perceptions of the REST paradigm via qualitative interviews.

Methods

- Participants included PwE ≥18 years of age, with a diagnosis of epilepsy or an epilepsy syndrome, and who had experienced ≥1 PS in the prior 12 months (defined as either a tonic-clonic or motor type seizure [lasting ≥2 minutes]; a non-motor seizure with impaired awareness or an absence seizure [lasting ≥2 minutes]; or a non-motor seizure when still aware [lasting ≥5 minutes]), and caregivers (≥18 years of age) of PwE (≥12 years of age) from France, Italy, Poland, Spain, the United Kingdom (UK), and the United States (US).
- Participants took part in 60- to 90-minute qualitative interviews regarding experiences with auras, epilepsy concepts, experience and unmet needs of acute medications, and perceptions of the REST paradigm.
- PwE answered questions/gave feedback regarding their own experiences; caregivers' experiences/observations were their own and caregivers were not answering on behalf of PwE.
- Interviews were recorded and analysed using formal qualitative coding techniques.

Results

PARTICIPANTS' CHARACTERISTICS AND SEIZURE EXPERIENCE

- 53 participants took part in qualitative interviews: 18 PwE ≥18 years of age, 18 caregivers of adult PwE (≥18 years of age), and 17 caregivers of adolescent PwE (≥12 to <17 years of age).
- 83% of participants were female; median (25th percentile [Q1], 75th percentile [Q3]) age was 47 (40, 51) years.
- Nine participants each were from France, Italy, Poland, the UK, and the US; 8 were from Spain.

Sociodemographic characteristics and seizure history

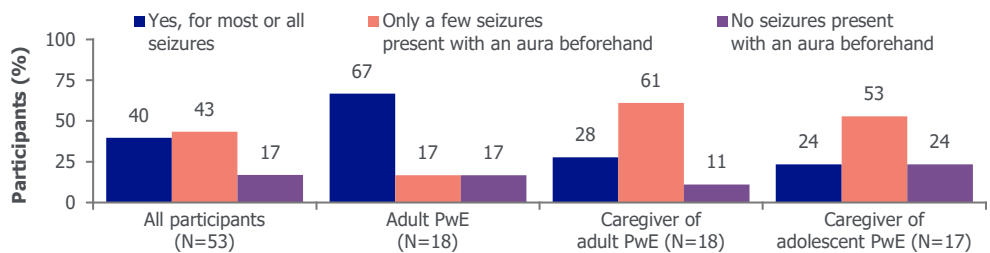
	Overall (N=53)	Adult PwE (≥18 years of age) (N=18)	Caregiver of adult PwE (≥12 to ≤17 years of age) (N=18)	Caregiver of adolescent PwE (≥12 to ≤17 years of age) (N=17)
Age of participant, median (Q1, Q3), years	47 (40, 51)	47 (30, 54)	50 (42, 56)	46 (39, 50)
Female, n (%)	44 (83)	11 (61)	17 (94)	16 (94)
Most common seizure types, ^a n (%)				
Generalized or bilateral seizures/tonic-clonic	35 (66)	9 (50)	13 (72)	13 (76)
Focal seizures without loss of awareness	22 (42)	7 (39)	8 (44)	7 (41)
Focal seizures with loss of awareness	20 (38)	7 (39)	8 (44)	5 (29)
Generalized or bilateral seizures non-motor	13 (25)	6 (33)	3 (17)	4 (24)
Unknown onset with present visible physical movement, jerks, or body stiffness	6 (11)	2 (11)	3 (17)	1 (6)
Unknown onset without any visible movements of the body or as an absence	3 (6)	1 (6)	1 (6)	1 (6)
Only experiences tonic-clonic seizures	14 (26)	2 (11)	5 (28)	7 (41)
Multiple seizure types	27 (51)	9 (50)	11 (61)	7 (41)
Average number of seizures per month during the prior 12 months, n (%)				
<3	12 (23)	6 (33)	2 (11)	4 (24)
3-5	17 (32)	6 (33)	6 (33)	5 (29)
6-10	6 (11)	2 (11)	3 (17)	1 (6)
11-20	5 (9)	2 (11)	2 (11)	1 (6)
>20	13 (25)	2 (11)	5 (28)	6 (35)
Average duration of most common seizure experienced during the prior 12 months, n (%)				
<1 minute	4 (8)	2 (11)	1 (6)	1 (6)
1-2 minutes	16 (30)	5 (28)	7 (39)	4 (24)
2-4 minutes	21 (40)	6 (33)	6 (33)	9 (53)
4-5 minutes	6 (11)	3 (17)	2 (11)	1 (6)
>5 minutes	6 (11)	2 (11)	2 (11)	2 (12)

^aMore than one category could have been selected. This study was completed before the 2025 updated seizure classification by the International League Against Epilepsy² was published. PwE, person with epilepsy; Q1, 25th percentile; Q3, 75th percentile.

- For caregivers (n=35), median (Q1, Q3) age of the PwE being cared for was 19 (15, 28) years.
- 71% of caregivers were parents and 63% had been caring for a PwE for >10 years.

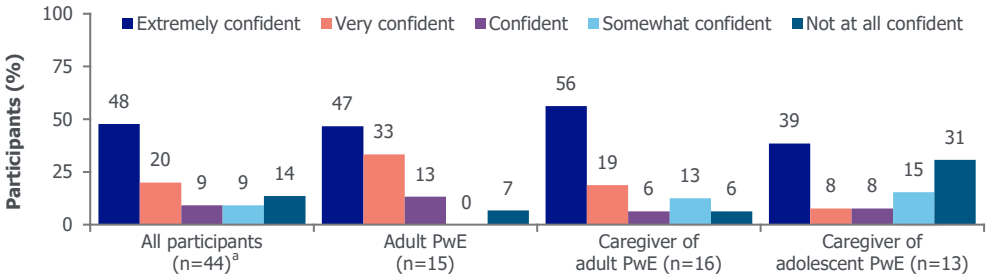
EXPERIENCE WITH AURAS

Aura or early symptoms at the very beginning of seizures^a



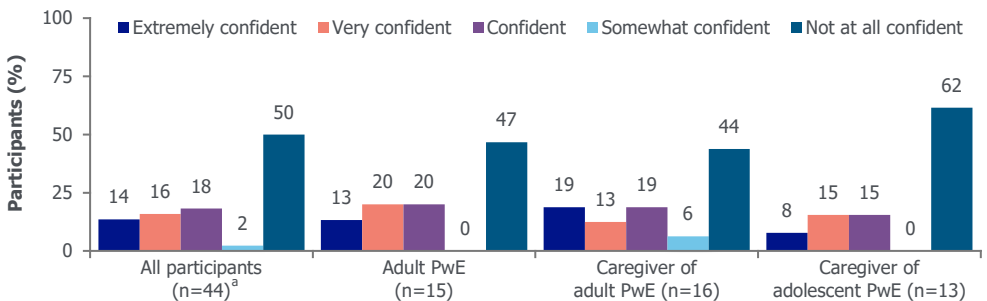
^aExperienced or observed by PwE or caregivers. PwE, person with epilepsy.

Confidence regarding aura or warning signs progressing to a seizure



^aNine participants reported not experiencing any auras or warning signs. PwE, person with epilepsy.

Confidence recognising an upcoming seizure as prolonged from experience with auras

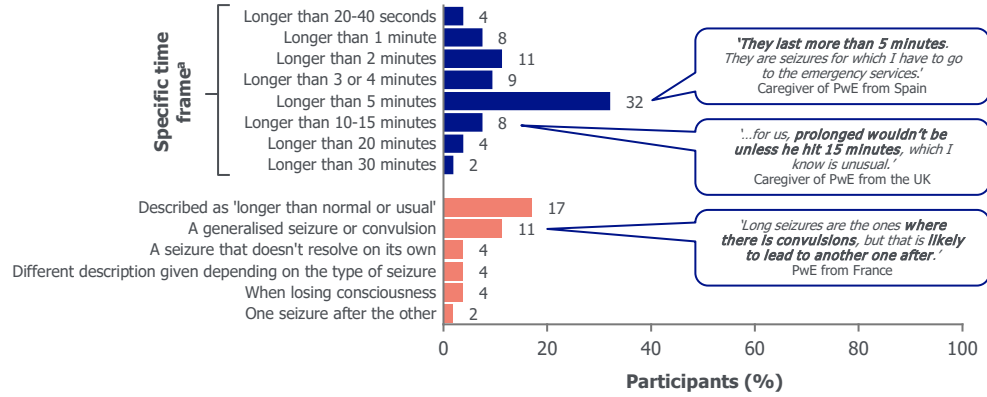


^aNine participants reported not experiencing any auras or warning signs. PwE, person with epilepsy.

KNOWLEDGE OF EPILEPSY CONCEPTS

- A specific time frame for the definition of a PS was given by 74% of participants.

Definitions of PS

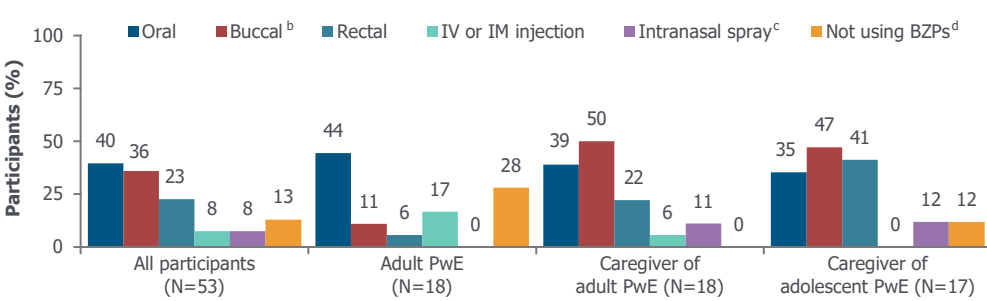


^aN=53. More than one definition could have been given. Five participants (9.4%) were missed or not asked about what they thought the definition of PS was. ^bTwo participants provided different timings depending on the type of seizure being discussed. PS, prolonged seizure; PwE, person with epilepsy; UK, United Kingdom.

CURRENT TREATMENTS AND UNMET NEEDS

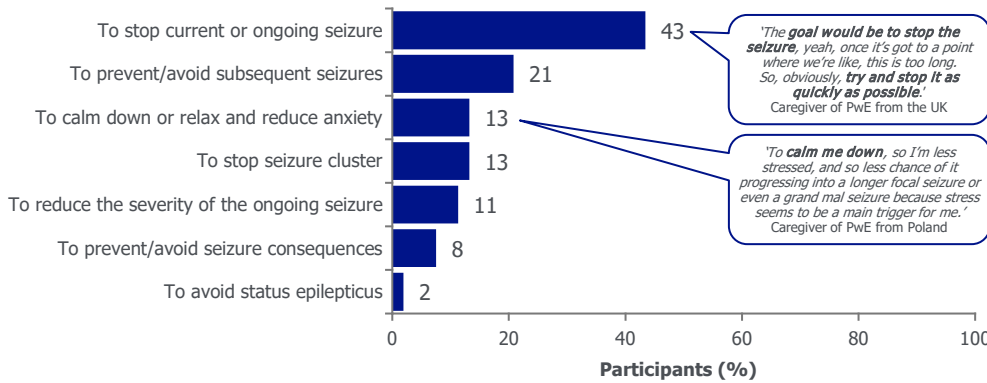
- 87% of participants used or administered a benzodiazepine as an acute medication for PS.

Modes of administration of current acute medications used to treat PS^a



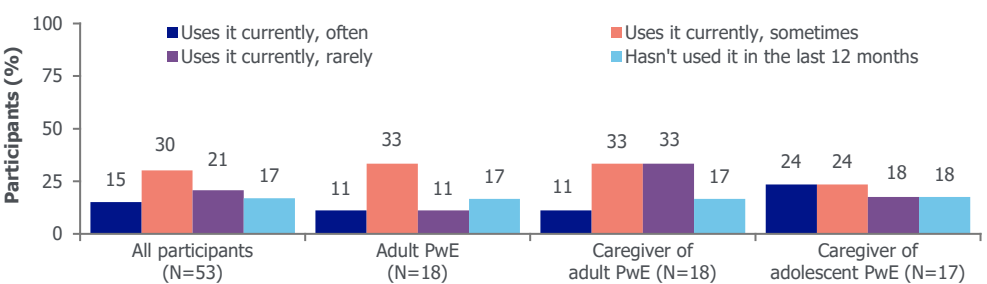
^aMore than one category could have been selected; ^bBuccal option was only available to participants in Europe; ^cIntranasal spray option was only available to participants in the United States; ^dNot using BZPs as acute medication to treat PS. BZP, benzodiazepine; IM, intramuscular; IV, intravenous; PS, prolonged seizures; PwE, person with epilepsy.

Main expectations/goals when using acute medication (N=53)^a



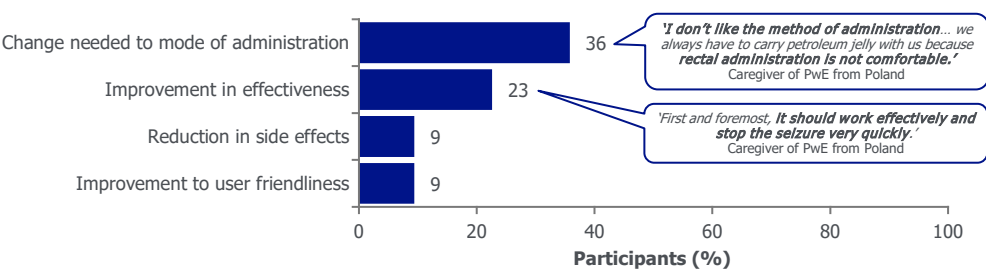
^aMore than one expectation/goal could have been given. PwE, person with epilepsy; UK, United Kingdom.

Experience with acute medication



PwE, person with epilepsy.

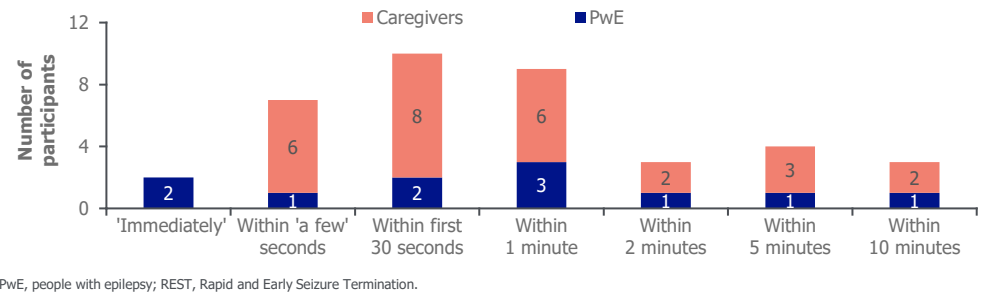
Changes participants would like to see regarding acute medication (N=53)



Only responses reported in ≥9% of participants are presented here. More than one view could have been stated. PwE, person with epilepsy.

PERCEPTIONS OF THE REST PARADIGM

Expectations regarding time for a REST medication to act (N=53)

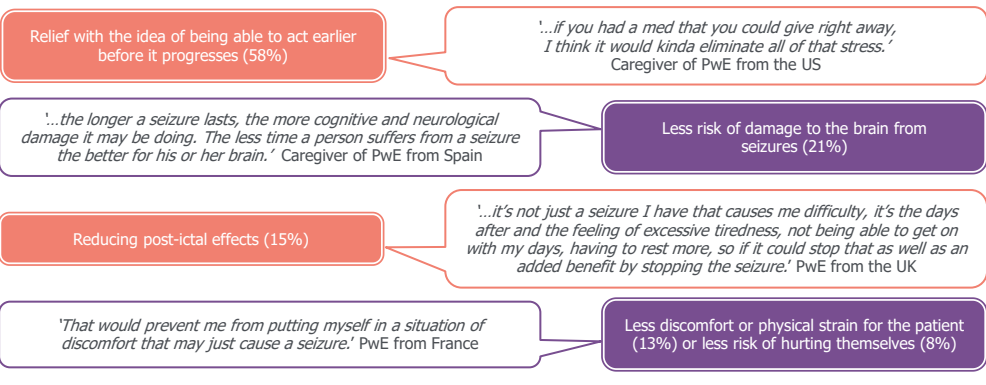


- 53% of participants (28/53) perceived a REST medication as quick/fast if it acts in ≤1 minute.

Perceptions of the REST paradigm

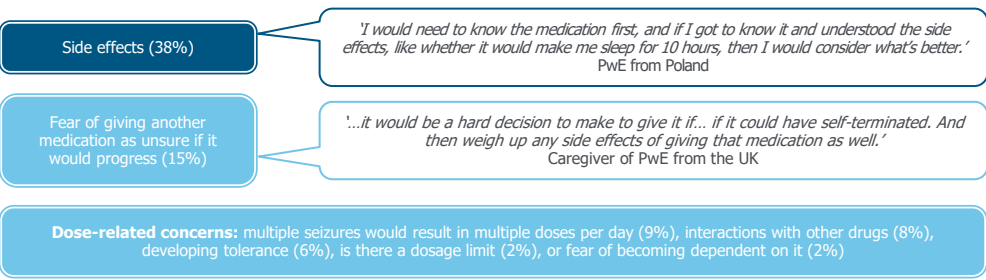
- The concept of REST (ie, treating seizures early with a fast-acting treatment) was explained to participants, and 15% (n=8/53) indicated they were already treating seizures early.
- 45 participants were not treating seizures early, of whom 67% (n=30/45) perceived REST to be a feasible approach.

Most mentioned perceived advantages regarding REST (N=53)^a



^aMore than one answer could have been given. PwE, person with epilepsy; REST, Rapid and Early Seizure Termination; UK, United Kingdom; US, United States.

Most mentioned perceived concerns regarding REST (N=53)^a



^aMore than one answer could have been given. PwE, person with epilepsy; REST, Rapid and Early Seizure Termination; UK, United Kingdom.

CONCLUSIONS

- Many participants reported they could confidently predict seizures based on auras.
- Most participants reported using or administering a benzodiazepine as acute medication for PS.
- Unmet needs of current acute medication were effectiveness (being more effective and/or quicker to act) and mode of administration.
- Most participants felt that REST is a feasible approach and suggested it could provide relief with being able to act earlier before seizures progress.
- This study highlights the unmet need for REST therapies; REST could be a beneficial and fast-acting approach to prevent seizures becoming PS or progressing in severity.

References

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