Poster 1.317

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

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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 aged ≥18 years, 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 (aged ≥18 years) of PwE (aged ≥12 years) 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 analyzed using formal qualitative coding techniques.

Results

PARTICIPANTS' CHARACTERISTICS AND SEIZURE EXPERIENCE

- 53 participants took part in qualitative interviews: 18 PwE aged ≥18 years, 18 caregivers of adult PwE (aged ≥18 years), and 17 caregivers of adolescent PwE (aged ≥12 to <17 years).
- 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 (aged ≥18 years) (N=18)	Caregiver of adult PwE (aged ≥18 years) (N=18)	Caregiver of adolescent PwE (aged ≥12 to ≤17 years) (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)

[a] More than one category could have been selected. This study was completed before the 2025 updated seizure classification by the International League Against Epilepsy[2] 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.

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 aged ≥18 years, with a diagnosis of epilepsy/epilepsy syndrome who had experienced ≥1 PS (≥2 minutes) in the prior 12 months and caregivers (aged ≥18 years) of PwE (aged ≥12 years). 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.

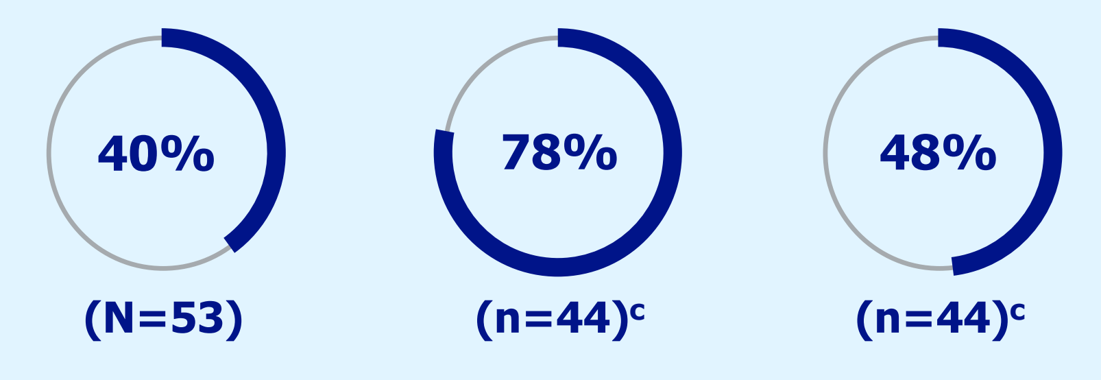
RESULTS

Experience with auras

Aura/early symptoms experienced/observed at the very beginning of most or all seizures

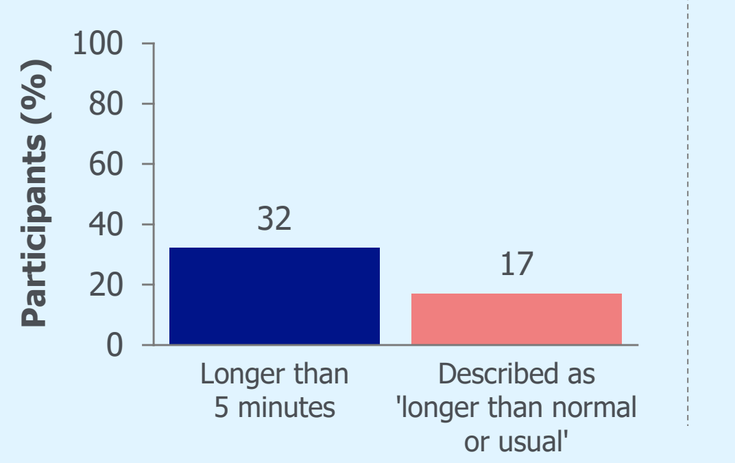
Confidence[a] on aura/warning signs progressing to a seizure

Confidence[a] recognizing an upcoming seizure as prolonged[b]



Knowledge of epilepsy concepts

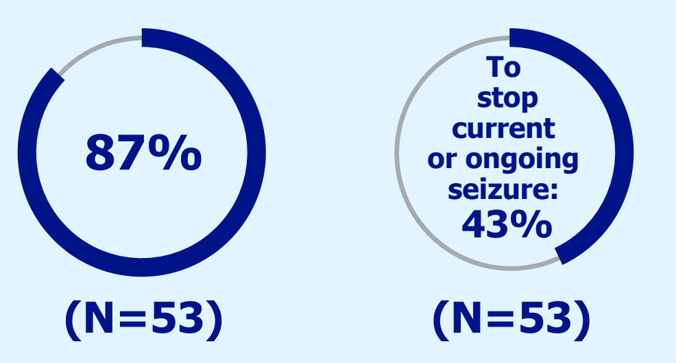
Most frequent definition of PS (N=53)[d]



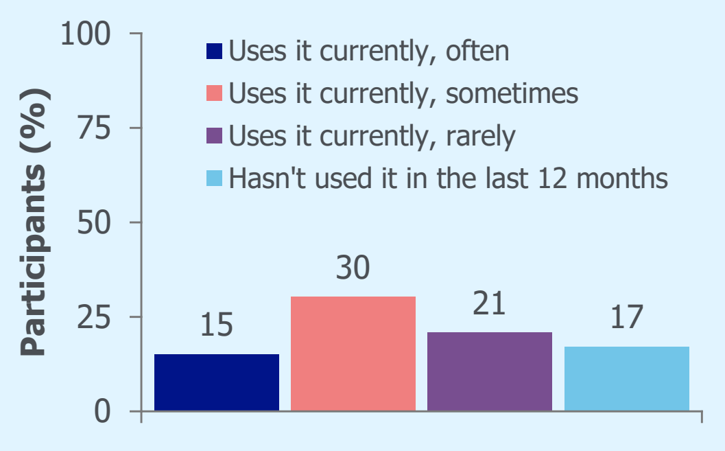
Current treatments and experience with acute medications

Using BZPs as acute medication to treat PS

Most common main expectation/goal[e] when using acute medication

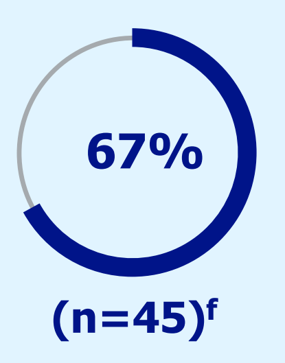


Experience with acute medication (N=53)

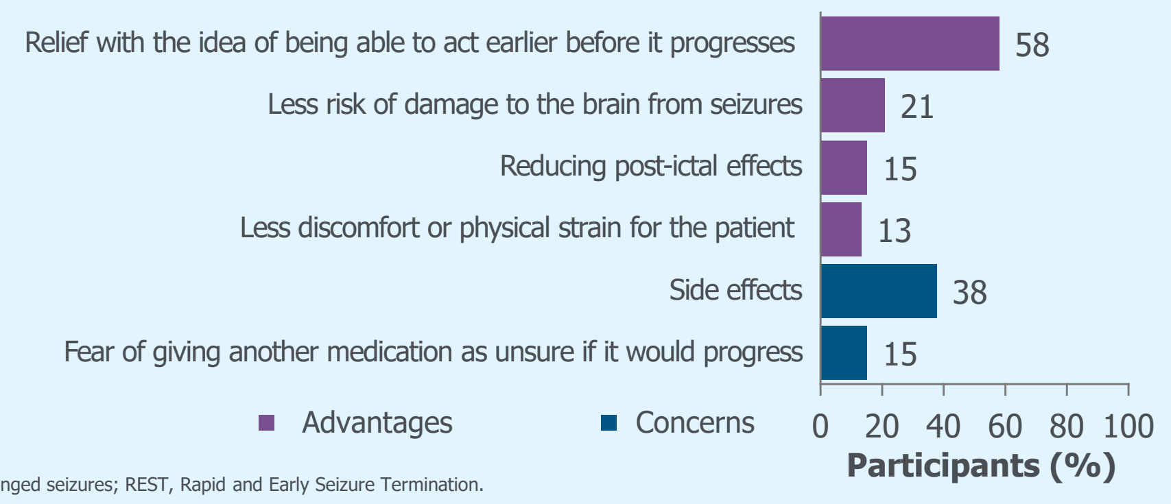


Perceptions of the REST paradigm

REST perceived to be a feasible approach



Perceived advantages and concerns regarding REST (N=53)[g]



[a] Extremely confident, very confident, or confident; [b] From participants' experience with auras; [c] Nine participants reported not experiencing any auras or warning signs; [d] More than one definition could have been given; [e] More than one expectation/goal could have been given; [f] Of 45 participants who were not treating seizures early; [g] Mentioned by >10% of participants; more than one answer could have been given. BZP, benzodiazepine; PS, prolonged seizures; REST, Rapid and Early Seizure Termination.

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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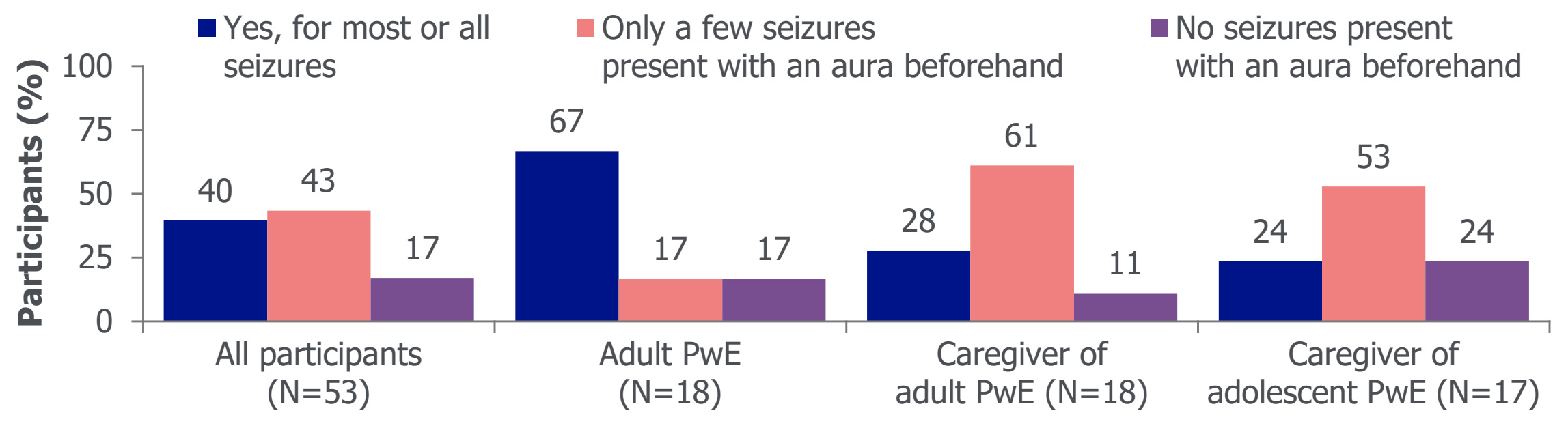
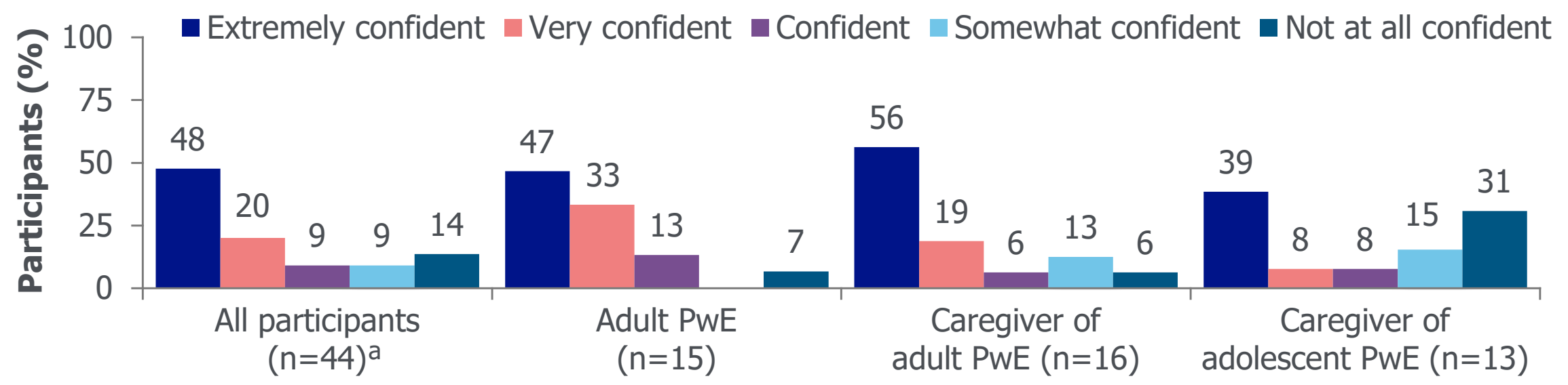
EXPERIENCE WITH AURAS

Aura or early symptoms at the very beginning of seizures[a]



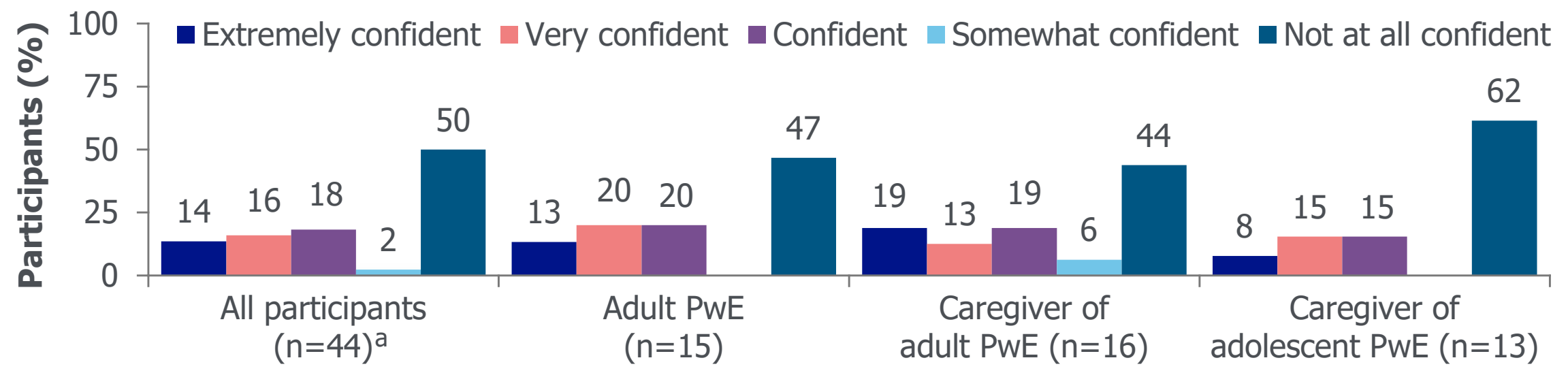
[a] Experienced or observed by PwE or caregivers. PwE, person with epilepsy.

Confidence regarding aura or warning signs progressing to a seizure



[a] Nine participants reported not experiencing any auras or warning signs. PwE, person with epilepsy.

Confidence recognizing an upcoming seizure as prolonged from experience with auras

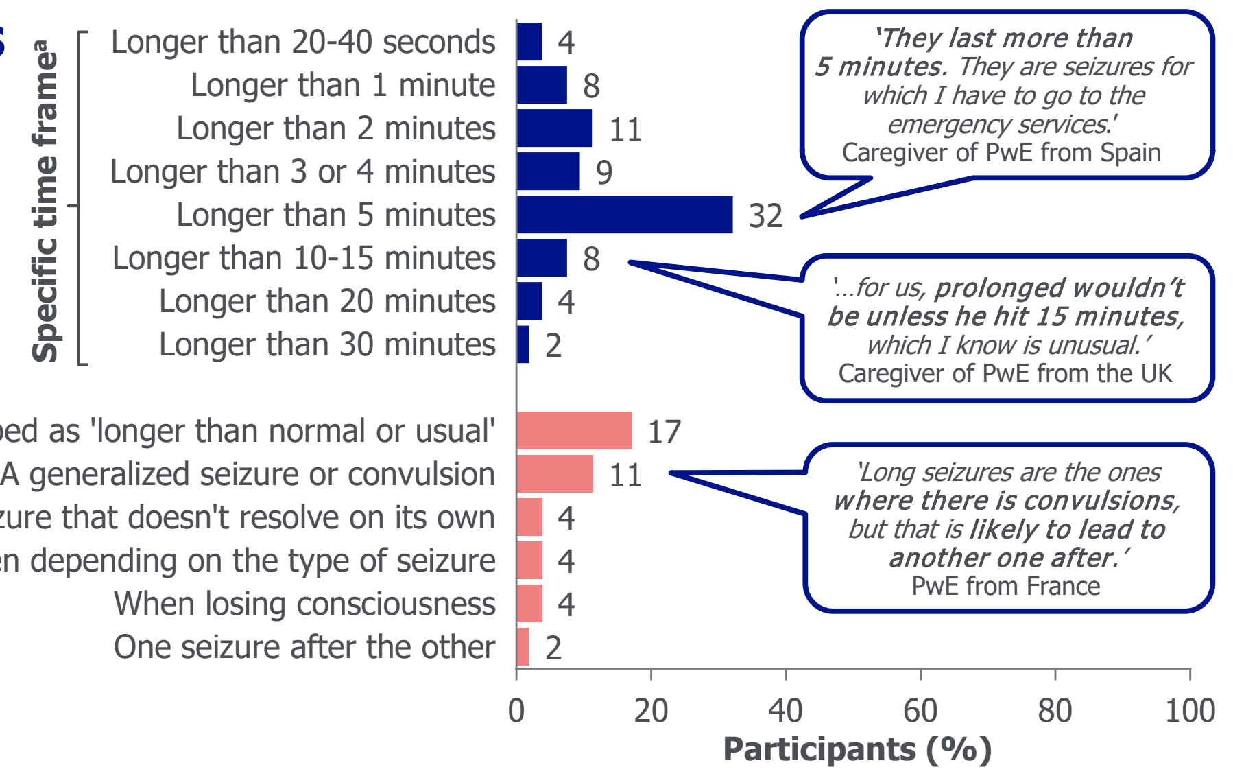


[a] Nine participants reported not experiencing any auras or warning signs. PwE, person with epilepsy.

KNOWLEDGE OF EPILEPSY CONCEPTS

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

Definitions of PS



*'They last more than **5 minutes**. They are seizures for which I have to go to the emergency services.'*
Caregiver of PwE from Spain

*'…for us, **prolonged wouldn't be unless he hit 15 minutes**, which I know is unusual.'*
Caregiver of PwE from the UK

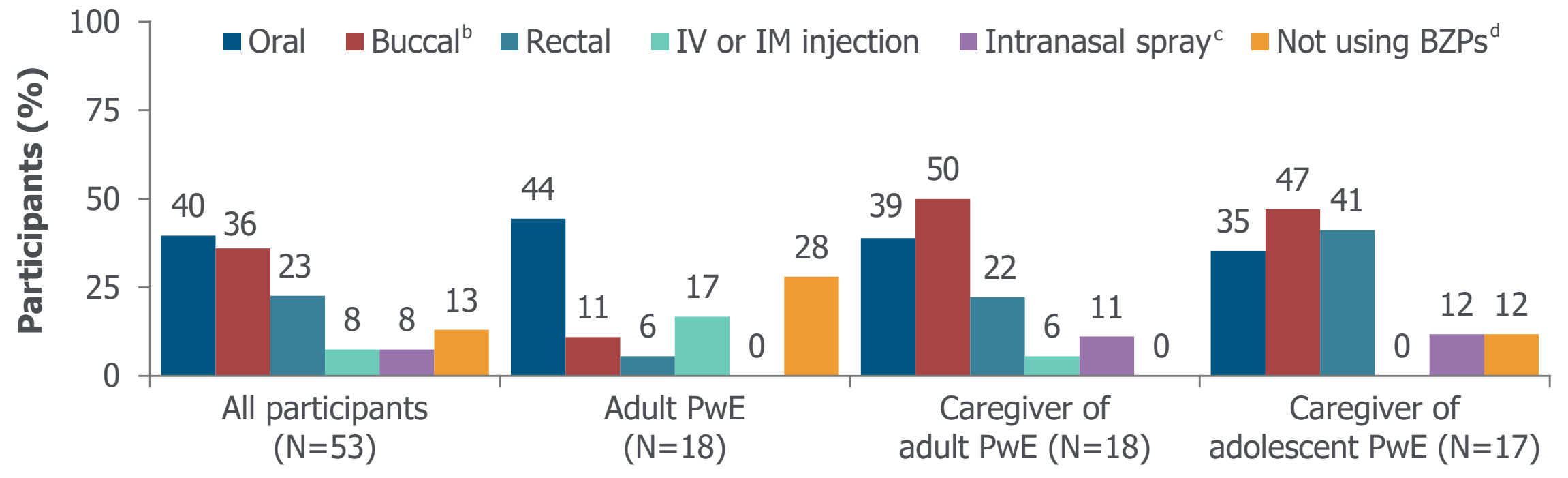
*'Long seizures are the ones **where there is convulsions**, but that is **likely to lead to another one after**.'*
PwE from France

N=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. [a] Two 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

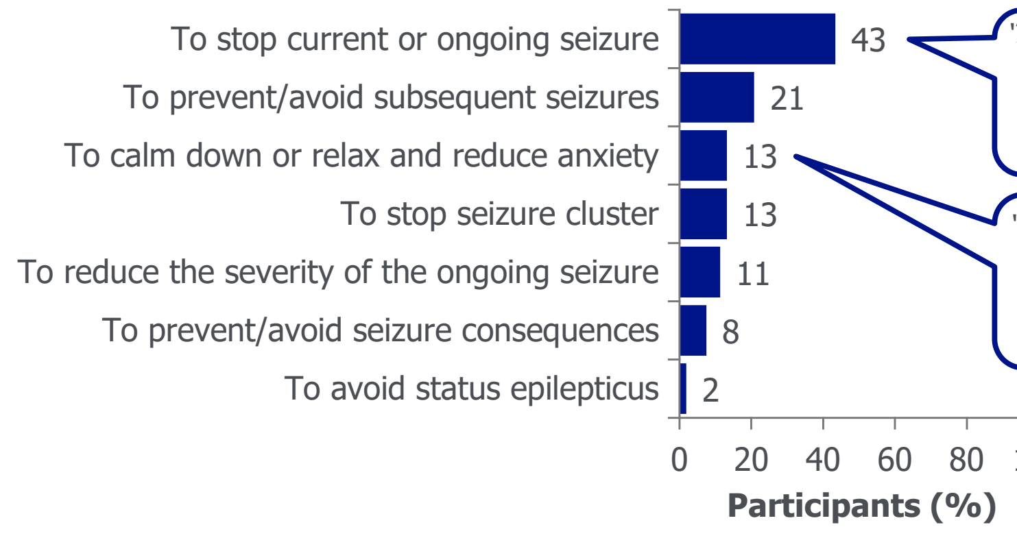
- 87% of participants used or administered a benzodiazepine as an acute medication for PS.

Modes of administration of current acute medications used to treat PS[a]



[a] More than one category could have been selected; [b] Buccal option was only available to participants in Europe; [c] Intranasal spray option was only available to participants in the United States; [d] Not 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]

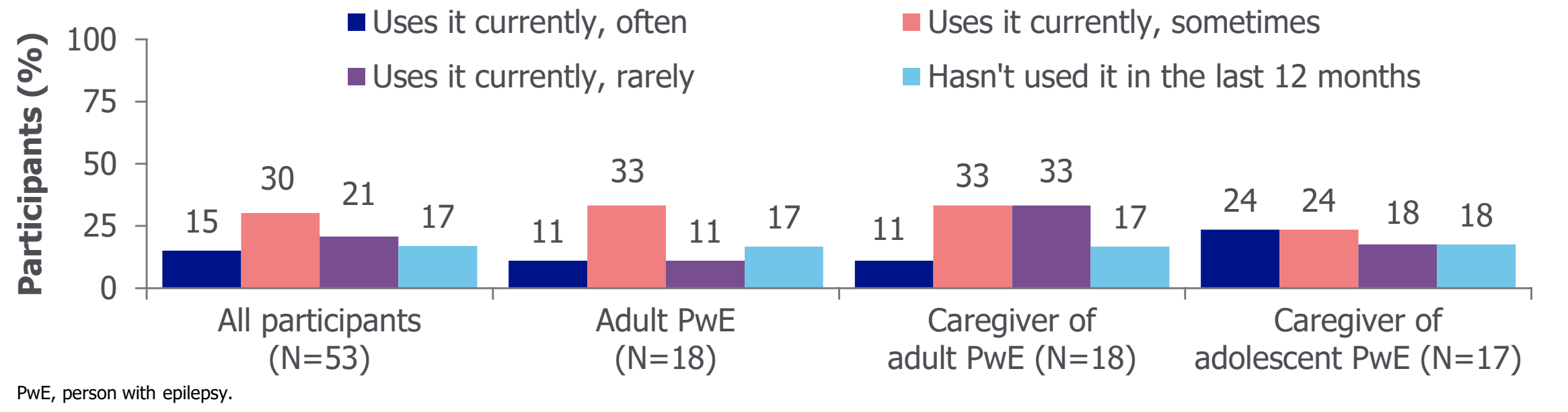


*'The **goal would be to stop the seizure**, yeah, once it's got to a point where we're like, this is too long. So, obviously, **try and stop it as quickly as possible**.'*
Caregiver of PwE from the UK

*'To **calm me down**, so I'm less stressed, and so less chance of it progressing into a longer focal seizure or even a grand mal seizure because stress seems to be a main trigger for me.'*
Caregiver of PwE from Poland

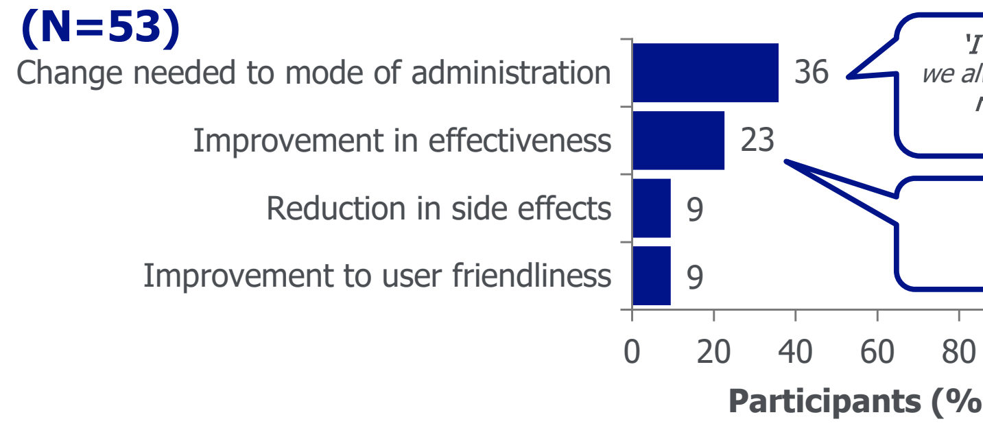
[a] More than one expectation/goal could have been given. PwE, person with epilepsy; UK, United Kingdom.

Experience with acute medication



PwE, person with epilepsy.

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



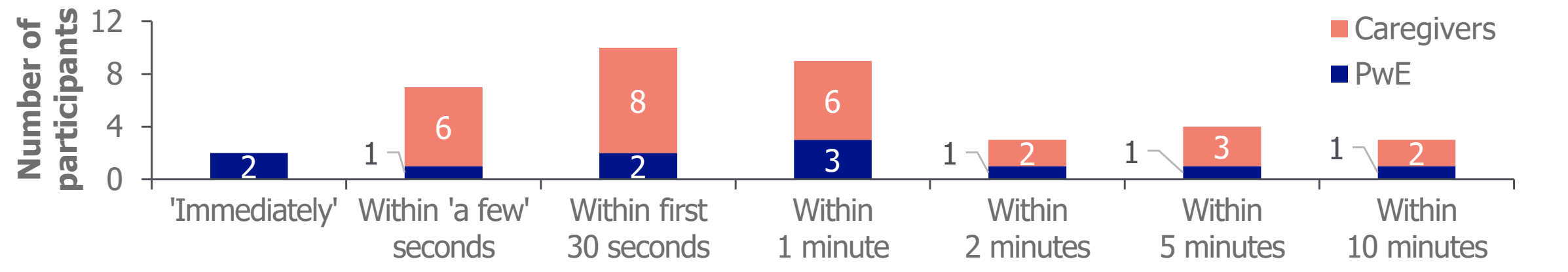
*'**I don't like the method of administration**… we always have to carry petroleum jelly with us because **rectal administration is not comfortable.**'*
Caregiver of PwE from Poland

*'First and foremost, **it should work effectively and stop the seizure very quickly.**'*
Caregiver of PwE from Poland

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)



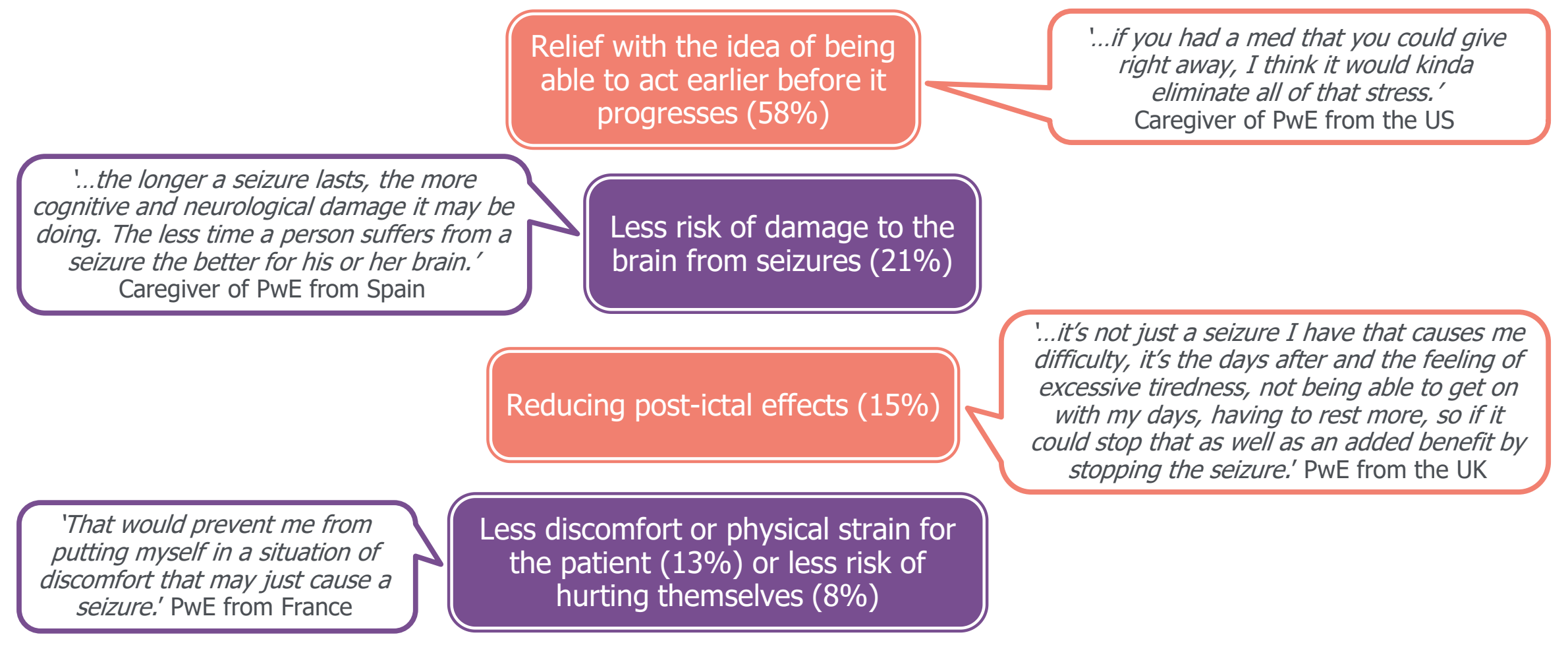
PwE, people with epilepsy; REST, Rapid and Early Seizure Termination.

- 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]



Relief with the idea of being able to act earlier before it progresses (58%)

'…if you had a med that you could give right away, I think it would kinda eliminate all of that stress.'
Caregiver of PwE from the US

Less risk of damage to the brain from seizures (21%)

'…the longer a seizure lasts, the more cognitive and neurological damage it may be doing. The less time a person suffers from a seizure the better for his or her brain.'
Caregiver of PwE from Spain

Reducing post-ictal effects (15%)

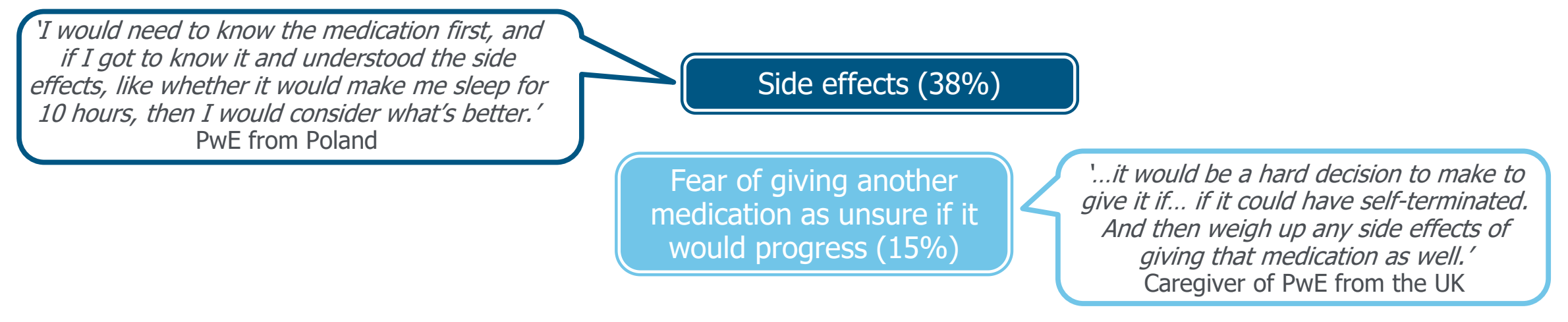
'…it's not just a seizure I have that causes me difficulty, it's the days after and the feeling of excessive tiredness, not being able to get on with my days, having to rest more, so if it could stop that as well as an added benefit by stopping the seizure.' PwE from the UK

Less discomfort or physical strain for the patient (13%) or less risk of hurting themselves (8%)

'That would prevent me from putting myself in a situation of discomfort that may just cause a seizure.' PwE from France

[a] More 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]



Side effects (38%)

'I would need to know the medication first, and if I got to know it and understood the side effects, like whether it would make me sleep for 10 hours, then I would consider what's better.'
PwE from Poland

Fear of giving another medication as unsure if it would progress (15%)

'…it would be a hard decision to make to give it if… if it could have self-terminated. And then weigh up any side effects of giving that medication as well.'
Caregiver of PwE from the UK

Dose-related concerns: multiple seizures would result in multiple doses per day (9%), interactions with other drugs (8%), developing tolerance (6%), is there a dosage limit (2%), or fear of becoming dependent on it (2%)

[a] More 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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