Poster P615

Characterising Patient and Caregiver Experiences Resulting From Prolonged Seizures

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QUESTION

What is the impact of prolonged seizures (PS) on people living with epilepsy (PwE) and their caregivers in Europe?

INVESTIGATION

Quantitative web surveys and qualitative 60-minute semi-structured interviews were conducted (June-August 2024) with 25 PwE (≥18 years; ≥3 PS lasting ≥2 minutes within past 3 years) and 25 caregivers from six European countries (United Kingdom, Germany, Spain, Italy, France, and Poland).

RESULTS

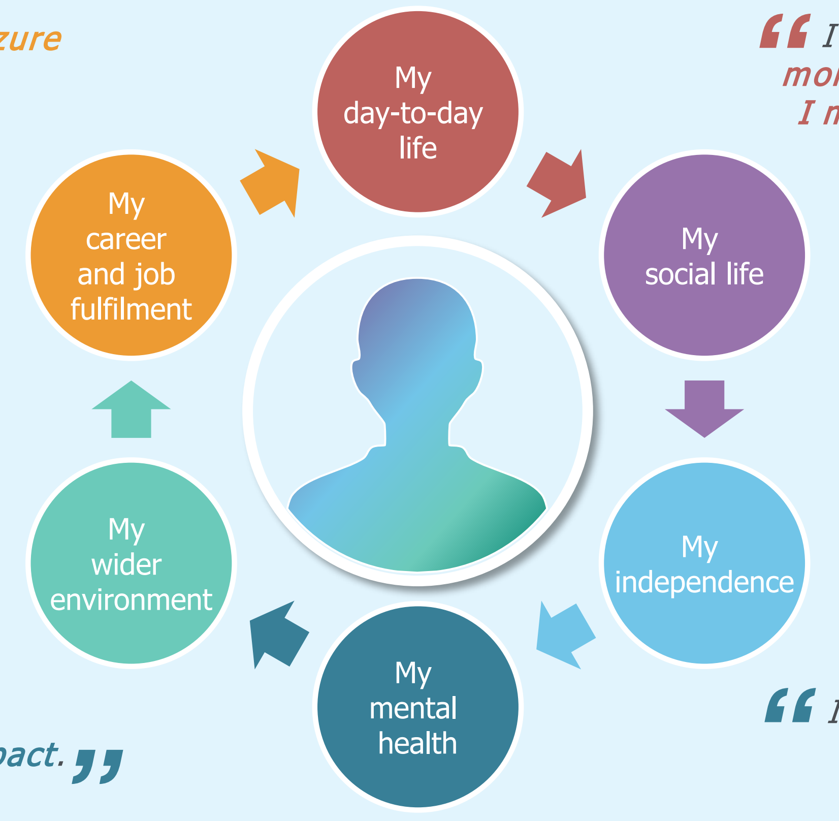
> “*I worry about my memory after a longer seizure* – that I will forget things at work.”
> PwE with PS

> “***It's much harder managing work after a longer seizure*** *– it takes me longer to get back to normal, I can't just jump back up and get on with things as before.*”
> PwE with PS

> “*You are always panicking … when you're witnessing a longer seizure [away from home] – you think you should know what to do, but you are just hoping that things calm down –* ***an extra 30 seconds compared to normal feels like a lifetime.***”
> Caregiver of PwE with PS

> “*I'm frightened, I have to go out, I have to shop for my children, I have to take them places, but I am constantly on edge and fearful of what might happen and* ***who is there to help me – especially if the seizure is longer or worse than normal.***”
> PwE with PS

> “*When I lost my driving license, I already felt isolated, this made it worse –* ***it makes you go into a downward spiral, it has a very real psychological impact.***”
> PwE with PS



> “*I always feel* ***embarrassed if I have a seizure in public, but it is felt so much more acutely for the longer ones – I'm lying there longer, more people see me, I might wet myself, it makes the stigma of having epilepsy so much worse*** *as I can't just bounce back and get on with my day.*”
> PwE with PS

> “***My social life is already restricted, but the chance of experiencing a longer seizure reduces it even further*** *as I'm much more likely to stay in familiar territory.*”
> PwE with PS

> “*Before, they would last a few minutes, but* ***now they can be longer*** *– we have to 'cushion him' a lot more since this change,* ***he did manage independently in the past, but not now.***”
> Caregiver of PwE with PS

> “*I do have fear – that it might be progressive – that it will have a cumulative impact on my health,* ***I'm afraid for the future – it stokes anxiety.***”
> PwE with PS

CONCLUSIONS

PwE and caregivers across Europe experience significant short- and long-term negative impacts on quality of life from PS. This highlights the importance of having more tools to support seizure management and control. This should include systematic adoption of seizure action plans paired with appropriate acute medications, including interventions for rapid and early seizure termination.

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Background

- Until recently, the term 'prolonged seizure' (PS) lacked a clear definition and was often used interchangeably with 'status epilepticus'.
  - Recently, an expert working group reached consensus on the definition of PS: 2 minutes for prolonged absence seizures and the convulsive phase of bilateral tonic-clonic seizures, and 5 minutes for prolonged focal seizures.[1]
- Studies have reported negative impacts of epilepsy on the quality of life (QoL) of people living with epilepsy (PwE) and their caregivers; however, the specific impact of PS on QoL is not well understood.

Objective

- To describe the unmet needs of PwE with PS and their caregivers across six European countries and assess the impact of PS on QoL.

Methods

- Quantitative and qualitative research was conducted across six European countries (United Kingdom, Germany, Spain, Italy, France, and Poland) from June through August 2024.
- A mixed methods approach was used, including a short quantitative web survey and qualitative semi-structured interviews (60 minutes).

PARTICIPANTS

- PwE ≥18 years who had experienced ≥3 PS (i.e. those lasting ≥2 minutes) within the past 3 years, without any severe comorbidities.
- Adult caregivers of PwE with PS.

ANALYSES

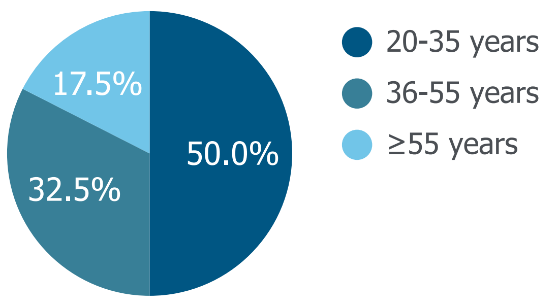
- The interviews were guided by interpretative phenomenological analysis to identify themes, attitudes, behaviours, and beliefs.[2]
- A qualitative inductive approach was also used for more in-depth and open-minded content.
- An iterative approach was taken by a single interviewer who conducted, transcribed, and analysed the interviews, refining the methodology as new insights were gathered; a second analyst assisted with verifying the themes to ensure consistency of interpretation.

Results

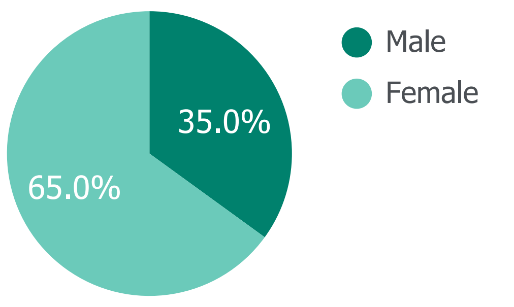
RESPONDENT DEMOGRAPHICS

- A total of 50 participants (25 PwE; 25 caregivers) participated in the study, and 40 participants completed the survey.

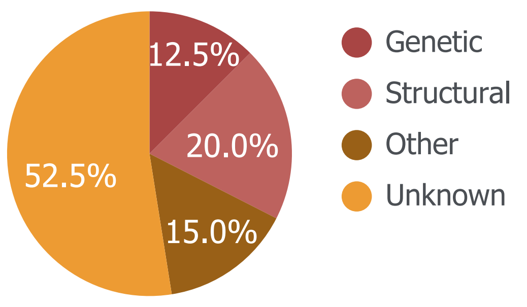
Age of PwE (n=40)



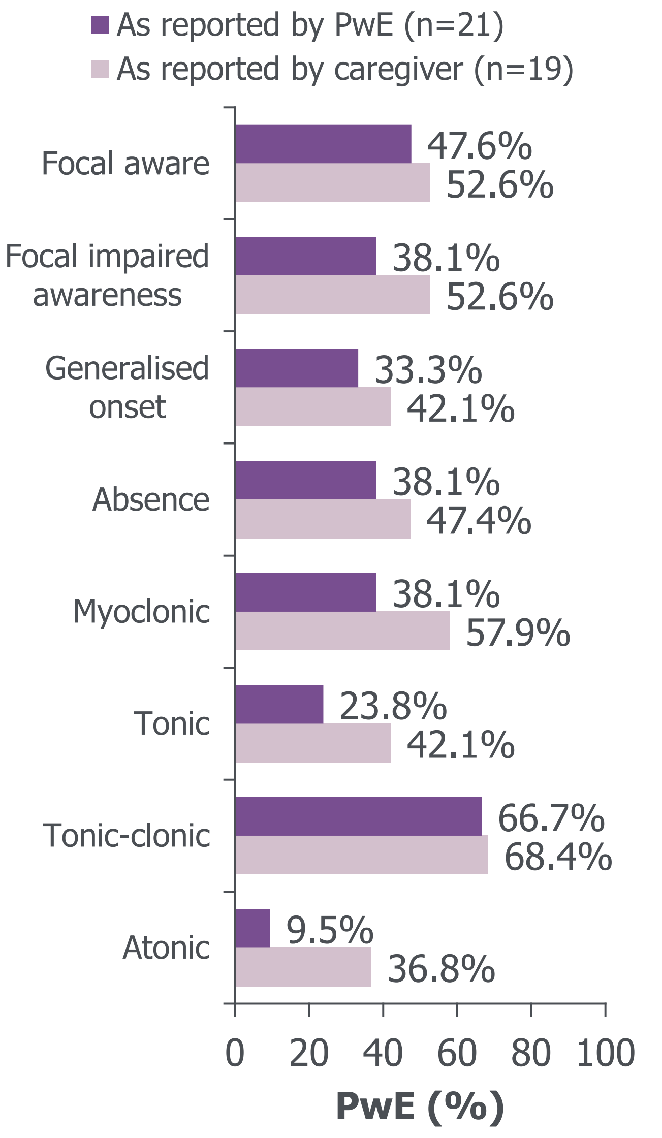
Sex of PwE (n=40)



Cause of epilepsy (n=40)



Seizure types experienced[a] (n=40)



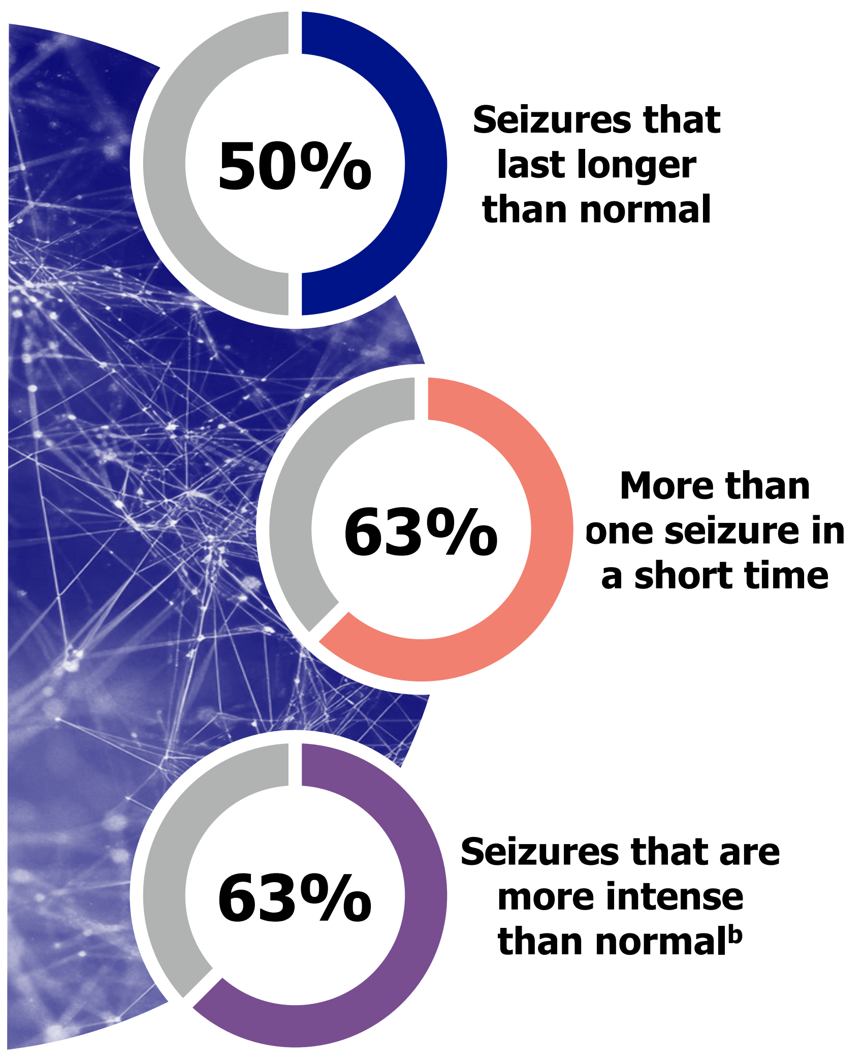
[a] Participants could have reported multiple seizure types. PwE, person living with epilepsy.

- Ten of 21 PwE (47.6%) reported experiencing >50 seizures per year.
- Nine of 21 PwE (42.9%) reported an average seizure duration of 1-2 minutes and 5 (23.8%) reported an average duration of 2-5 minutes.

PROLONGED SEIZURES ARE PARTICULARLY CONCERNING

- 50% of participants reported that seizures lasting longer than usual are particularly worrying; 63% of participants reported that seizures that were more intense than normal or more than one seizure in a short period of time were also particularly troubling.
- PwE and caregivers perceived prolonged seizures differently based on individual experiences, including different seizure durations (>30 seconds to >5 minutes), symptoms experienced during or after the seizure, seizure types, seizure frequency, and risk of injury.

Factors that participants reported as particularly concerning[a] (n=40)



> *'The longer it goes on, the more damaging it might be and the more concerned we become.'* – Caregiver of PwE with PS

> *'The longer the seizures are, the longer the recovery phase takes. In the past, with the big seizures, he also had sore muscles for days, muscle pain, etc., migraine, sensitivity to light for days.'* – Caregiver of PwE with PS

> *'Clusters are the worst – you feel the strength completely drain from your body – no strength in my legs or able to move following these clusters. I was kept in hospital; it was the worst experience of my life – I was fearful that this was the end. I thought that they would never stop.'* – PwE with PS

> *'It is machine-like, one after the other. Seizure, break, seizure, break. Like that all the time. It can last for a very long time. It could go on for an hour or even longer for such seizures – could be 20, 30, 40 seizures.'* – PwE with PS

> *'If I could have one thing to help, it would be something to make it less intense, less severe because of how this impacts him afterwards – he is out of it really for 3-4 days, but the cumulative impact is important too.'* – Caregiver of PwE with PS

> *'When I say 'more violent' it relates mainly to the aftermath – because I don't feel the seizures per se, it's mainly upon waking up I feel the difference.'* – PwE with PS

[a] Participants could choose more than one option; [b] Many of these participants mentioned intensity of the post-ictal state and recovery. PS, prolonged seizures; PwE, person living with epilepsy.

IMPACT OF PROLONGED SEIZURES

- For most participants, the impact of PS was an extreme version of problems they face from seizures in general, but there were some specific areas of exacerbated impact.

Impact on seizure control

- PS make PwE/caregivers more aware of their lack of control over seizures
- PS present greater risk of physical injury (especially if in an unfamiliar environment)
- PS increase inability to control breathing

Impact on mental health

- PS increase anxiety, stress, and risk for depression, which can trigger further seizures for PwE
- Mood swings before/after PS are more pronounced
- Confusion and memory loss persist after a PS
- Fears/worries about immediate impacts are more extreme with PS
- PS also increase fear of long-term brain damage

Impact on independence

- PS are more likely to require interventions, making it harder for PwE to live alone and drive, and heightening feelings of being a burden
- PwEs' perceptions and concerns over their lack of seizure control, memory loss, recovery time, and stigma in work settings negatively impact their careers

Impact on social life

- PwE/caregivers often limit social life due to risk and fear of PS, as they feel more confident in familiar environments
- PwE also report PS having a negative impact on their romantic and parental relationships as well as friendships
- Planning is difficult due to the condition's unpredictability
- Impact on family planning, especially for young women

> *'These longer ones are more extreme – the worst I have experienced, the mood swings before were extreme … On the day of the seizure, I will be having anxiety-based symptoms all day … and I become scared – it causes me to panic more in anticipation, which makes things worse of course.'* – PwE with PS

> *'He feels he is really missing out on things … he has had to stop work and still wants to do much more with his life, but the possibility of a long seizure, maybe needing an ambulance, stops him from experiencing those things.'* – Caregiver of PwE with PS

Conclusions

- PwE and caregivers across Europe emphasize seizure duration as a particularly troubling factor, alongside perceived seizure intensity and occurrence of seizure clusters.
- PwE and caregivers experience significant short- and long-term negative impacts on QoL from PS.
- This highlights the importance of having more tools to support seizure management and control.
  - This should include systematic adoption of seizure action plans paired with appropriate acute medications, including interventions for rapid and early seizure termination[1].

References

1. Pina-Garza JE, et al. *Epileptic Disord* 2024;26(4):484-497.
2. Larkin M, et al. *Qual Res Psychol* 2019;16(2):182-198.

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