

Bridging the Divide: Enhancing Communication Between People Living With an Epilepsy and Their Healthcare Providers to Improve Care

Background

- Effective communication between patients and their healthcare providers (HCPs) is important to improve the quality of care for people living with an epilepsy (PwE).¹
- A recent quantitative and qualitative research study conducted in six European countries described the unmet needs of PwE with prolonged seizures (PS) and their caregivers and assessed the impact of PS on their quality of life (QoL).²

Objectives

- To explore the experiences of PwE living with PS and their caregivers.
- To identify ways to improve communication between PwE/caregivers and their HCPs, thereby increasing PwE/caregivers' confidence, knowledge, and self-management, and ultimately enhancing QoL.

Methods

- Qualitative research was conducted between May and August 2024 in six European countries (United Kingdom, France, Germany, Italy, Poland, Spain).
- A mixed methods approach was used, which involved brief quantitative pre-interview surveys and 60-minute qualitative deep-dive interviews.
- The study included PwE ≥ 18 years of age who had experienced ≥ 3 PS (lasting ≥ 2 minutes) within the past 3 years (with no severe comorbidities^a) and adult caregivers of PwE with PS.
- The definition of PS was based on a recent consensus definition: > 2 minutes for prolonged absence seizures and the convulsive phase of bilateral tonic-clonic seizures, and > 5 minutes for prolonged focal seizures.³

^aAny comorbidities apart from those related to epilepsy that would have dominated their health (eg, cancer).

Results

- 50 participants (25 PwE; 25 caregivers) took part in this study.
- PwE with PS saw HCPs 1-4 times per year, and all expressed a desire for more frequent access to their neurologists rather than waiting for routine appointments.
- HCPs and PwE do not have aligned definitions and interpretations of what it means to have seizure control.
- PwE expressed interest in learning about and discussing controllable aspects of their epilepsies with their HCPs, such as stress and sleep management.
- PwE who were able to discuss topics beyond seizures with their HCP felt better equipped to manage their epilepsy and achieve a greater sense of control.
- Both PwE and caregivers felt that better understanding of seizure patterns (including recognition of prodromes and auras) as well as response strategies would improve their sense of control.
- As caregivers were often required to respond to seizures, they preferred more direct contact with HCPs and sought clearer guidance on seizure management.
- Most PwE and caregivers lacked understanding and training on rescue medications and seizure action plans.

QUESTION

What improvements in communication do people living with an epilepsy (PwE) who experience prolonged seizures (PS) and their caregivers need from their healthcare providers (HCPs)?

INVESTIGATION

Qualitative research in six European countries (United Kingdom, France, Germany, Italy, Poland, Spain) using a mixed methods approach, involving brief pre-interview surveys and 60-minute qualitative deep-dive interviews. Participants: PwE ≥ 18 years of age who had experienced ≥ 3 PS (lasting ≥ 2 minutes) within the past 3 years (with no severe comorbidities) and adult caregivers of PwE with PS.

RESULTS

PwE and caregiver need more holistic conversations with their HCPs around impact and management of their condition

PwE with PS need:

- 15-20 minutes of their time is **not enough** when you are having a lot of seizures, when things are changing, when things don't feel under control. – PwE with PS, Spain
- It's really hard during the consultation to spend time asking about the things that really matter to me, such as what I should or shouldn't be doing in my life to **help manage my epilepsy** – there's only ever enough time to **discuss the medication**. You have to be very assertive and brave as a young patient to bring up other things. – PwE with PS, Germany
- When the seizures became longer, I started to question everything again – can my life plan stay the same? Will I be a good mother? It's the **longer-term psychological burden** that I really need help with. – PwE with PS, Spain

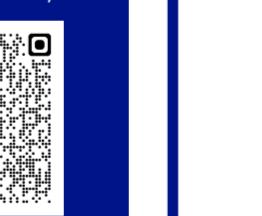
Caregivers need:

- Managing the seizures is one thing, but managing what comes with that – **the anxiety, the loss of self**, is quite another. – PwE with PS, Italy
- I would like more preparation. Some tips, something caregivers can do ... to shorten the duration or to spare me the crisis. – PwE with PS, Italy
- I've never been given any information around what to expect, what to do. Am I doing everything right? – Caregiver, UK

CONCLUSIONS

PwE with PS, especially those dealing with unpredictable seizures and/or changes in seizure patterns, want to have more holistic conversations with their HCPs around management of their epilepsy to increase their sense of control and improve their quality of life. These conversations should include lifestyle modifications, seizure action plans, discussions around seizure patterns (including prodromes and auras), information around how and when to intervene, training around use of rescue medications, and communication around topics beyond antiseizure medications that affect the QoL of those impacted by an epilepsy.

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Perceptions of seizure control

- PwE with PS seek to obtain a sense of control over their epilepsy, which extends beyond discussions around antiseizure medications and rescue medications into areas where they feel unsupported (eg, lifestyle management, non-seizure outcomes).
- PwE want to have more holistic conversations with their HCPs around management of their epilepsy.

PwE with PS describe their seizure management experiences in various ways

↑ 'Controlled' ↓ 'Uncontrolled'

Seizure-free 'at the moment' Treatment is controlling seizures for now and PwE with PS are hopeful that this will continue but aware that things might change as they have in the past

Seizures are partially 'under control' Seizures continue to be part of life, but PwE with PS and caregivers have found ways to deal with them as they occur and work hard to contain things

Seizures are 'managed'^{a,b} Seizures occur frequently and the focus is on managing them as well as possible. However, the frequency and impact feel unsustainable

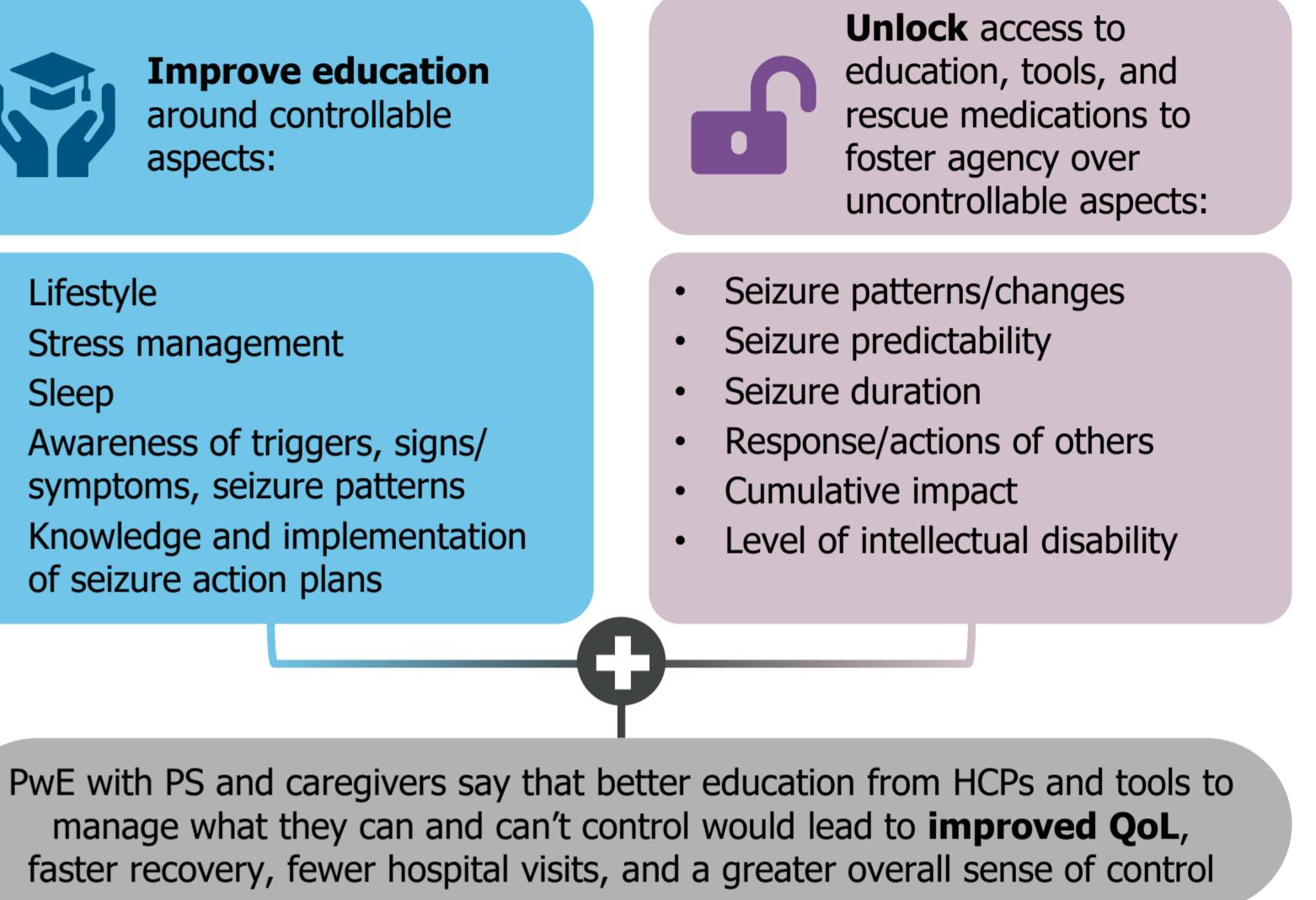
Seizures are 'invasive'^b Seizures feel constant and invasive; ASMs are changed during hospital admissions or when changes to seizure patterns occur and ASM regimen can be complex

^aWhen PwE with PS talked about seizures being 'controlled', they were referring mainly to the ASM regimen they have been prescribed; however, when they talked about 'managing' their seizure pattern, they were referring to their own ability to stay in control, doing their best to mitigate seizures, and managing them better when they occur; ^bSeizures are unpredictable and have a negative impact on QoL.

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How can HCPs support PwE with PS to improve their sense of control?



Conclusions

- PwE with PS would benefit from more holistic conversations with their HCPs that go beyond discussions of medications and seizure frequency, and include guidance on areas that matter to patients: lifestyle issues, mental health, emotional wellbeing, seizure action plans, seizure patterns, emergency response, and long-term management.
- PwE with PS and HCPs often have different views on what seizure control means. Aligning these perspectives could lead to more personalized and effective care.
- Improved education and practical tools to manage both controllable and uncontrollable aspects of the condition would lead to improved QoL, faster recovery, fewer hospital visits, and a greater overall sense of control.
- Better communication between PwE, caregivers, and HCPs can build confidence, reduce psychological burden, support appropriate use of rescue medications, and decrease reliance on emergency care.

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