'When I am away from home, we must be

more careful about the emergency rescue plan.

If the seizure is not responding after 5

minutes, then we call an ambulance. But when

I am at home [and] the situation is under

control, they know they can wait 1-2 minutes

more before calling an ambulance."

- PwE, male, age 36-45 years

'I have the same definition for

seizure emergency in home vs. out

in public [...] At home, we can

manage things more and it is not as

embarrassing.'- Caregiver, male,

of PwE age 26-35 years

'Anytime she has clusters, I

consider it a seizure emergency

and go straight to the hospital.

They are not the typical pattern.

Caregiver, female,

of PwE age 36-45 years

'Severity based on body

language.' - Caregiver, male,

of PwE age 46-55 years

Impact of Prolonged Seizures on Patients' and Caregivers' Quality of Life

'It's the recovery, intensity and

inability to take care of myself or

others – I can be down for 2-3 days.'

- PwE, female, age 36-45 years

Physical

Cognitive

My speech is slurred and I can't

think of words. The memory

challenging. How did I lose that

[...] time? It's chunks of my life

PwE, female, age 46-55 years

taken out. It's very frustrating.'

gaps are emotionally

can't do anything without

asking somebody to help me

PwE, female,

age 46-55 years

'Had seizures that ultimately cost

me my job because of seizures at

work. I lost an amazing career

that I had worked really hard

to create [...] I am on

- PwE, female, age 46-55 years

disability now.'

People living

with epilepsy

or take me somewhere.

Q RESULTS

CONFUSION

MENTAL HEALTH

emotional well-being

concerns mentioned

Mental health and

were among the

in this study.

PwE mentioned physical

effects including shallow

breathing, nausea,

extreme fatigue, loss of

vision, headache/migraine,

tongue injuries, burns,

ead fractures, and broken

PwE mentioned cognitive

effects including confusion,

disorientation, brain fog,

memory gaps, limited word

retrieval, slurred speech,

communication difficulties,

and aggression.

E CONCLUSIONS

'After the seizure, I have blurry vision

for 1–2 hours. I have dizziness for

30–40 minutes. I have lingering

fatigue. I get the blues and feel sad

and gloomy; my mood changes and

I don't want to talk and do anything.

– PwE, male, age 36-45 years

Danya Kaye¹ Michelle Manzo² Andrea L Wilkinson³ Cédric Laloyaux⁴ Rebecca Burns² Jesús E Piña-Garza⁵ Joseph I Sirven⁶ Tanya Bhatia⁷ **Shalee Cunneen**⁸ Shelly Meitzler⁹ Susan Linn¹⁰

ررمر

ANXIETY

1. UCB, Morrisville, NC, USA

DURING A SEIZURE?^a

'If it is lasting longer than her usual

seizure [...] They usually take a couple of

seconds up to 3 minutes; so anything past

that, I would say is an emergency."

Caregiver, female, of PwE

age ≥55 years

The longer it lasts, the more we

are concerned. The longer the

seizure, the more severe it is.'

– PwE, male, age <20 years</p>

- 2. UCB, Smyrna, GA, USA
- 3. UCB, Emeryville, CA, USA 4. UCB, Brussels, Belgium
- 5. Centennial Children's Hospital, Nashville, TN, USA 6. Department of Neurology, Mayo Clinic, Jacksonville, FL, USA
- 7. Patient author, Chicago, IL, USA
- 8. Caregiver author, CURE Epilepsy, Chicago, IL, USA 9. Caregiver author, TSC Alliance, Silver Spring, MD, USA

WHAT IS THE MAIN DRIVER FOR INTERVENING

40% Seizure duration

17% Seizure clusters

13% Seizure type

- **13%** Perception of seizure intensity

7% Specific physical signs

^a5 participants did not answer this question; some participants gave >1 answer; n=30.

17% Location

10. Epilepsy Foundation New England, Lowell, MA, USA

Background

- Until recently, the term 'prolonged seizure' (PS) was not well defined and was frequently used synonymously 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 Several studies have reported the negative impact of epilepsy on patients' and
- caregivers' quality of life (QoL); however, the impact and associated burden specific to PS is unknown.

Objective

 To describe experiences of people living with epilepsy (PwE) with PS and their caregivers, identify their unmet needs, determine greatest areas of burden, and assess the impact of PS on QoL.

Methods

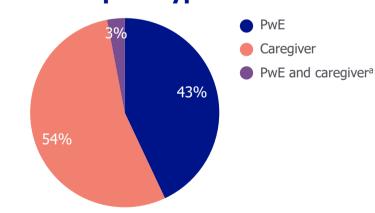
- Quantitative and qualitative research was conducted from September 2023 through January 2024 to characterize the burden of PS on PwE and caregivers.
- A mixed methods approach was used, including a pre-interview survey (\sim 15 min) and qualitative interviews (90-120 min).
- Inclusion criteria: US-based PwE ≥18 years of age or caregivers of PwE ≥12 years of age; PwE were currently experiencing or had a recent history of seizures that typically last ≥2 min and usually do not stop on their own or worsen over time.

Results

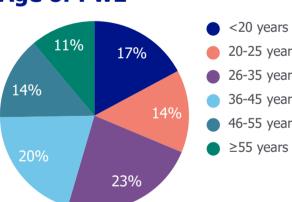
RESPONDENT DEMOGRAPHICS

- 35 participants completed the pre-interview survey and qualitative interviews.
- Age and sex of PwE were well balanced; PwE were from a wide range of ethnicities.
- PwE experienced a wide range of seizure types, seizure durations, and seizure frequencies.

Participant type

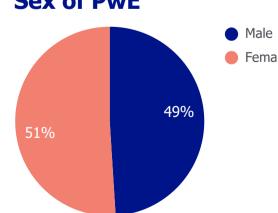


Age of PwE

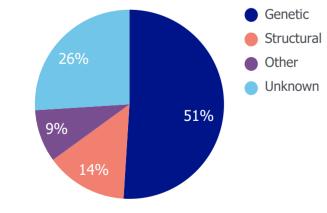


20-25 years 26-35 years 36-45 years 46-55 years

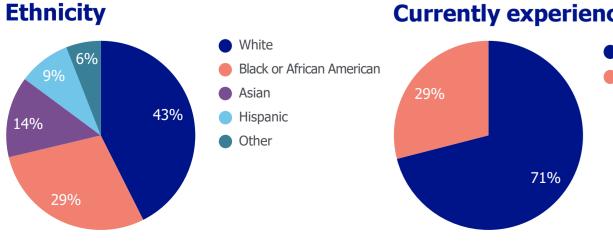
Sex of PwE



Cause of epilepsyb



Currently experiencing PS^b



'She feels embarrassed if she has a prolonged seizure in public. This is what led to her suicide attempts. If she's at home, she's used to it, but she still gets sad.' – Caregiver, female, of PwE age 26-35 years

'It definitely took a toll on my mental

health and my self-esteem because it

ruined my tongue and the way I talked.

And then when it came time to hanging

out with friends, I always felt like I was

the burden [...] It felt like something very embarrassing.

PwE, female, age 26-35 years

EMOTIONAL WELL-BEING S & MENTAL biggest challenges and HEALTH by PwE and caregivers

90% of participants experienced

- 90% (26/29) of participants experienced anxiety and/or depression,
- therapy to help manage their mental health, whereas 40% (14/35) did not.
- Caregivers consistently reported that they feel extremely worried about their loved one experiencing a PS – before, during, and after the seizure.

my sister, but it gets worse around the time when she experiences prolonged seizures.' – Caregiver, female, of PwE age 36-45 years

'In the beginning, I had a lot of depression and anxiety directly related to caring for my husband. My mental health condition was not very good. Now I talk to a doctor that gives me medication and I was able to heal and accept the situation and learn from it.' - Caregiver, female, of PwE age 36-45 years

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

'I was transparent about anxiety and depression, but I was not transparent about how bad it would get; how much despair I felt; how 'Lost all my independence, debilitating it was; about

suicidal ideation.'

PwE, male,

age 46-55 years

'It was so hard to have my

[daughter] not feel

comfortable [...] being

around me and seeing

what was going on.'- PwE,

female, age 46-55 years

motional/mental heal

PwE mentioned emotional/mental

health effects, including irritability,

ow mood, stress, anxiety, depression

suicidal ideation/attempts,

embarrassment/shame, lack of

independence, inability to work, guilt

ssociated with dependence and burden

on loved ones, disappointment, anger,

worry, low confidence/self-esteem, and

social isolation.

*71% (25/35) of participants reported they/their loved ones were currently experiencing PS.

'Even when it's not something that needs medical intervention, sitting and waiting is the most powerless, helpless feeling you can have. '- Caregiver, female, of PwE age 36-45 years

The **biggest challenges** reported

by caregivers during a PS included

keeping loved ones safe to avoid

injuries, physically moving loved

ones, and the responsibility to

decide when to administer rescue

ambulance.

seizures in public, or rectal rescue

administration).

medication and if/when to call an

'I am worried he won't wake up and die. After, I am relieved. Caregiver, female, of PwE age 36–45 years

They report experiencing fear around when next seizure will occur, fear of loved one dying/SUDEP guilt (especially when epilepsy has a genetic cause), worry and stress about impact of seizures, as well as depression and anxiety.

Caregivers' mental health and emotional

well-being are significantly impacted by PS.



Emotions most mentioned included feeling helpless, powerless, and out of control, fear and uncertainty of the outcome, as FAMILY 5 well as the short- and long-term DISCONNECT impact of the PS. Caregivers also mentioned a pressure to stay calm, concern around dealing with loved one's recovery, the pain associated with watching seizures, and embarrassment (especially during

'At times we have been neglected by our own families because of the condition. They think when they come to our home to visit, they will get epilepsy; like it's contagious. PwE, female, age 46-55 years

POST-ICTAL RECOVERY PERIOD

care for others.

Caregivers mentioned an impact on their finances/ability to work, ability to take care of other family members, and isolation from

aily life/work/social li

family/friends.

PwE reported additional challenges with the PS post-ictal recovery period, including

• 83% (29/35) of participants correlated seizure duration with longer recovery time.

physical injuries, feeling weak or tired, and/or temporary inability to return to work or

come out of this? What impact is this going to have in the brain?'

Caregiver, female, of PwE age <20 years

PwE, people living with epilepsy; SUDEP, sudden unexpected death in epilepsy.

'It has done a lot to me mentally [and] emotionally.

It is a really overwhelming experience. I can't do

what I used to do. I can't hang with my friends. I

miss out. It is not easy to be a caregiver.'

Caregiver, male, of PwE age 26-35 years

'I worked full time and I found I couldn't

be away 8-12 hours a day, so I quit doing

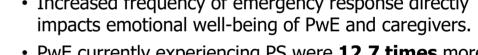
that. I now work part time at Door Dash

case something happens.' - Caregiver,

female, of PwE age 36-45 years

...] A lot of times I take her for the ride in

EMERGENCY RESPONSE Increased frequency of emergency response directly



• PwE currently experiencing PS were 12.7 times more likely to experience a seizure emergency^{a,b} and **4 times** more likely to call an ambulance^c than PwE not currently experiencing PS.

Self-reported by participants based on their interpretation of seizure emergency; Average of 11.3 (n=24) vs 0.9 (n=9) per year; ^cAverage of 3.2 (n=22) vs 0.9 (n=9) per year.

'There's a lot of panic, there's a lot of anger, a lot of emotions that [you] are going through because you're now inside the back of an ambulance or even at a hospital or you are just in a different position than you were [...] And it's terrifying, absolutely terrifying.' PwE, female, age 46-55 years

Conclusions

- The negative health impact of PS on PwE and caregivers is profound.
- PS represent a significant burden to PwE and their caregivers that results in reductions to their QoL through impact on mental and emotional health, cognition, and physical recovery. Disruptions to daily life, ability to work, and social isolation are negative consequences of PS.
- Unmet needs in treatment, care, and support remain. There is an opportunity to build resources for social, emotional, and psychological support for PwE experiencing PS and their families.

Reference

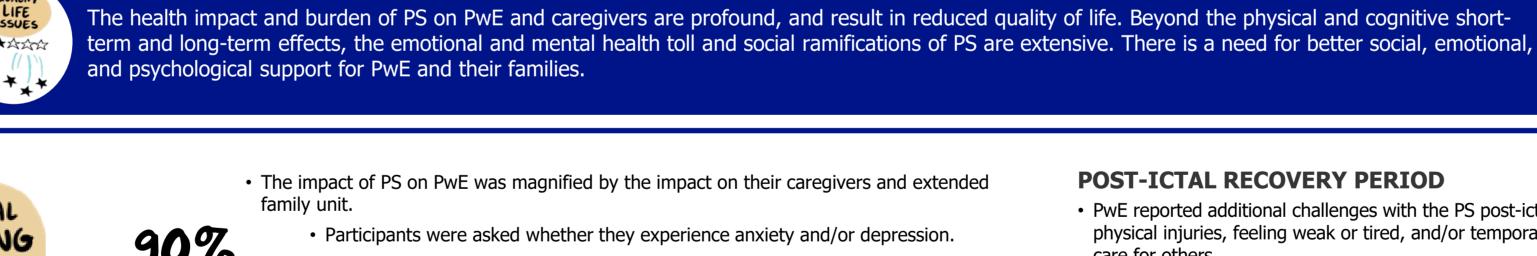
1. Pina-Garza JE, et al. *Epileptic Disord* 2024;26(4):484-497. https://doi.org/10.1002/epd2.20243

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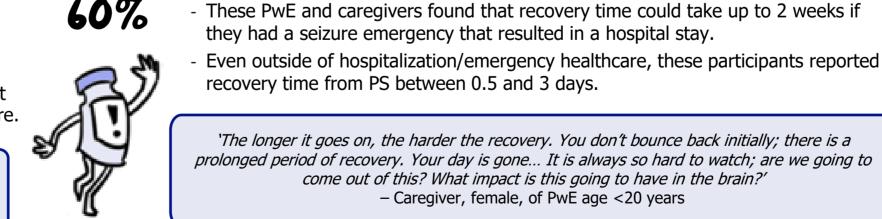
Previously presented at American Epilepsy Society 78th Annual Meeting, Los Angeles, CA, USA,

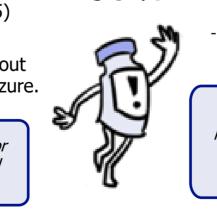


- and 10% (3/29) reported no significant mental health impact.
- 60% (21/35) of participants reported receiving medication/seeking

'I have anxiety all the time. I didn't have any anxiety before I started caring for

'It has impacted a lot because everyone is on their toes. We all feel stressed. We don't have good sleep (just worry). The fear is there. It has affected everyone.' - Caregiver, male, of PwE age 26-35 years





recovery time from PS between 0.5 and 3 days.

'The longer it goes on, the harder the recovery. You don't bounce back initially; there is a prolonged period of recovery. Your day is gone... It is always so hard to watch; are we going to

 Those participants who did not perceive a correlation between seizure length and recovery time typically reported shorter recovery periods of up to a few hours, and all reported seizures to be well-controlled.

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