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

'My speech is slurred and I can't

think of words. The memory

gaps are emotionally

taken out. It's very frustrating.

PwE, female, age 46-55 years

challenging. How did I lose that

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WHAT IS THE MAIN DRIVER FOR INTERVENING DURING

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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

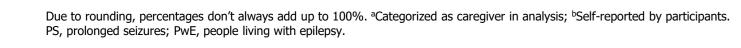
- Ouantitative and qualitative research was conducted from September 2023 through January 2024 to characterize the burden of PS on PwE and caregivers.
- A mixed methods approach was used, including a pre-interview survey (~15 min) and qualitative interviews (90-120 min).
- Inclusion criteria: US-based 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 years</p> Caregiver 20-25 years PwE and caregiver^a 26-35 years 36-45 years 46-55 years Cause of epilepsyl Structural Other Unknown **Currently experiencing PS**^b Black or African American



CONFUSION **MENTAL HEALTH** Mental health and emotional well-being were among the biggest challenges and concerns mentioned by PwE and caregivers in this study. 'It definitely took a toll on my mental health and my

QUESTION

RESULTS

WE mentioned physical

preathing, nausea, extreme

fatique, loss of vision,

neadache/migraine, tongue

injuries, burns, head

ractures, and broken bones.

effects including confusion,

disorientation, brain fog,

memory gaps, limited word

retrieval, slurred speech,

communication difficulties,

and aggression.

E CONCLUSIONS

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

'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

'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

EMOTIONAL

HEALTH

effects including shallow

psychological support for PwE and their families.

'Lost all my independence,

can't do anything without

asking somebody to help me o

take me somewhere.'- PwE,

People living

with epilepsy

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

I am on disability now.

- PwE, female, age 46-55 years

of participants

experienced Caregivers consistently reported that they feel extremely worried about their loved one experiencing a PS – before, during, and after the seizure.

'I have anxiety all the time. I didn't have any anxiety before I started caring for my sister, but it gets worse around the time when she experiences prolonged seizures. '- Caregiver, female, of PwE age 36-45 years

10% (3/29) reported no significant mental health impact.

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

notional/mental hea

mentioned emotional/mental health

effects, including irritability,

low mood, stress, anxiety, depression

suicidal ideation/attempts,

embarrassment/shame, lack of

ndependence, inability to work, guilt

on loved ones, disappointment, anger,

worry, low confidence/self-esteem, and

social isolation.

ssociated with dependence and burden

'I was transparent about

anxiety and depression, but .

was not transparent about

how bad it would get; how

much despair I felt; how

debilitating it was; about

suicidal ideation.'- PwE,

male, age 46-55 years

'It was so hard to have my

comfortable [...] being

around me and seeing what

female, age 46-55 years

was going on. - PWE,

'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

The impact of PS on patients was magnified by the impact on their caregivers and extended family unit.

Participants were asked whether they experience anxiety and/or depression.

to help manage their mental health, whereas 40% (14/35) did not.

- 90% (26/29) of participants experienced anxiety and/or depression, and

60% (21/35) of participants reported receiving medication/seeking therapy

'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

PwE age 36–45 years

'Even when it's not something

that needs medical intervention,

sitting and waiting is the most

powerless, helpless feeling you

PwE age 36-45 years

an have.' - Caregiver, female, of

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 medication and if/when to call an ambulance.

The **biggest challenges** reported

Emotions most mentioned included feeling helpless, powerless, and out of control, fear and uncertainty of the outcome, as well as the short- and long-term 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 seizures in public, or rectal rescue

administration).

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

The health impact and burden of PS on PwE and caregivers are profound, and result in reduced quality of life. Beyond the physical and cognitive short-term

and long-term effects, the emotional and mental health toll and social ramifications of PS are extensive. There is a need for better social, emotional, and

DISCONNECT 'At times we have been because of the condition. They think when they come to our epilepsy; like it's contagious.' PwE, female, age 46-55 years

FAMILY

'I am worried he won't

wake up and die.

After, I am relieved.

- Caregiver, female, of

Caregivers

POST-ICTAL RECOVERY PERIOD

time from PS between 0.5 and 3 days.

well-controlled.

seizure emergency that resulted in a hospital stay.

Caregivers mentioned an impact on their finances/ability to work ability to take care of and isolation from family/friends.

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

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

injuries, feeling weak or tired, and/or temporary inability to return to work or care for others.

- These PwE and caregivers found that recovery time could take up to 2 weeks if they had a

- Even outside of hospitalization/emergency healthcare, these participants reported recovery

'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 come out of this?

What impact is this going to have in the brain?' – Caregiver, female, of PwE age <20 years

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

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Caregivers' mental health and emotional

well-being are significantly impacted by PS.

guilt (especially when epilepsy has a genetic

as well as depression and anxiety.

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EMERGENCY RESPONSE

 Increased frequency of emergency response directly impacts emotional well-being of PwE and caregivers.

• 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.

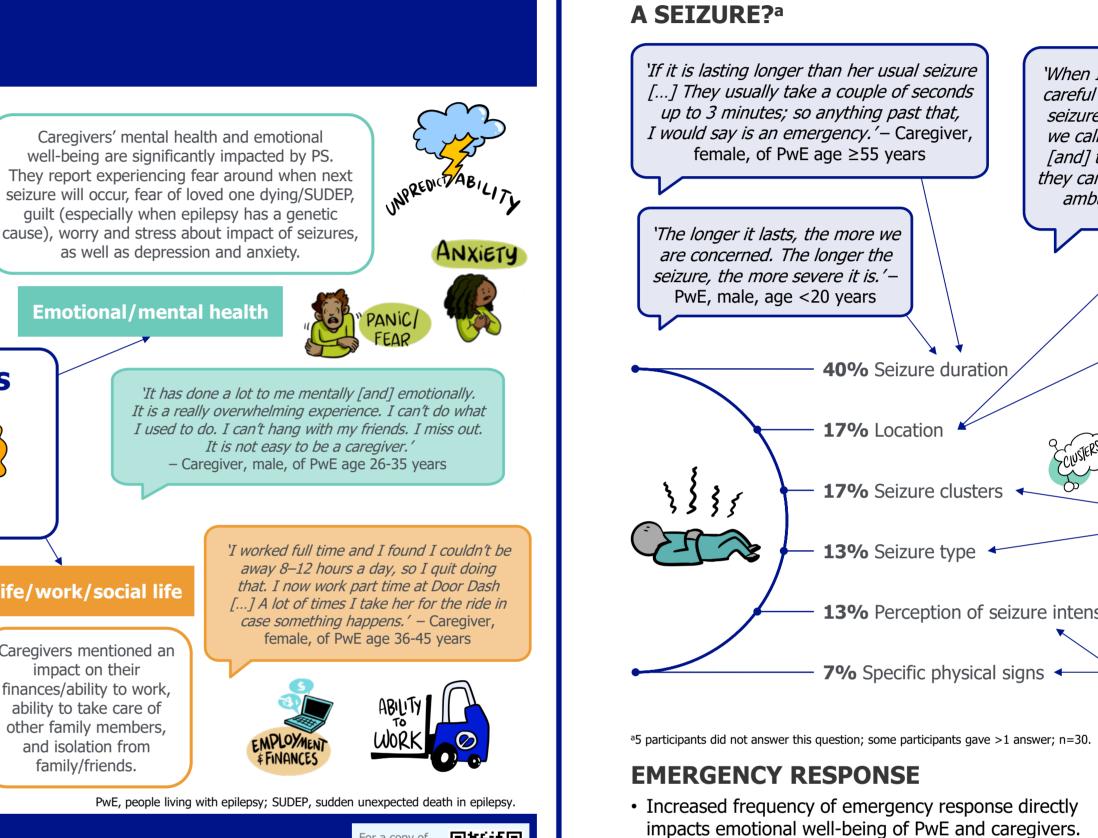
^aSelf-reported by participants based on their interpretation of seizure emergency; ^bAverage of 11.3 (n=24) vs 0.9 (n=9) per year;

'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.'

- PS represent a significant burden to PwE and their caregivers that results in reductions to
- 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

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

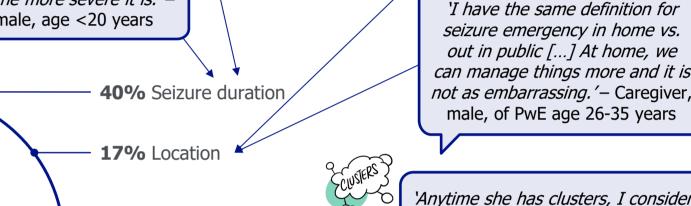
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'If it is lasting longer than her usual seizure 'When I am away from home, we must be more [...] They usually take a couple of seconds up to 3 minutes; so anything past that, *I would say is an emergency.'* – Caregiver,

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 female, of PwE age ≥55 years [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

'The longer it lasts, the more we are concerned. The longer the seizure, the more severe it is.'-PwE, male, age <20 years



17% Seizure clusters ←

it a seizure emergency and go straight to the hospital. They are not the typical pattern.' - Caregiver, female, of PwE age 36-45 years 13% Perception of seizure intensity

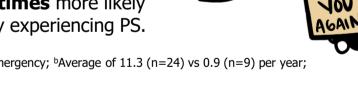
'Severity based on body **7%** Specific physical signs ← *language.'* – Caregiver, male, of PwE age 46-55 years











Average of 3.2 (n=22) vs 0.9 (n=9) per year.

- PwE, female, age 46-55 years

Conclusions

- The negative health impact of PS on PwE and caregivers is profound.
- 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.
- their families.

Reference



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