

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

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

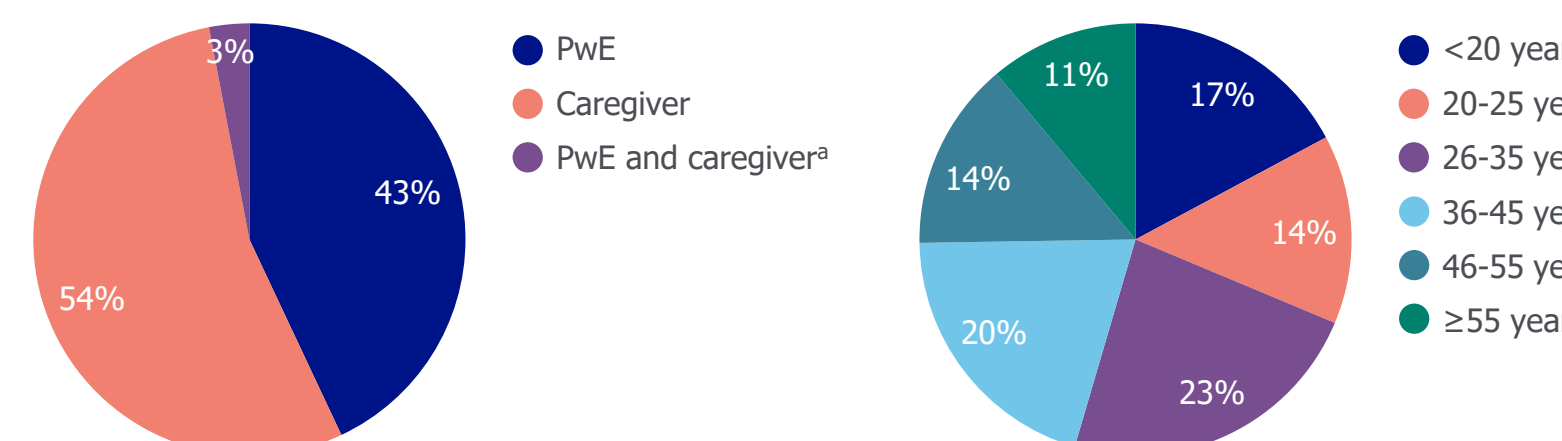
- Quantitative and qualitative research was conducted from September 2023 through January 2024 to characterize the burden of PS on PwE and caregivers.
- A mixed methods approach was used, including a pre-interview survey (~15 min) and qualitative interviews (90-120 min).
- Inclusion criteria: US-based 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

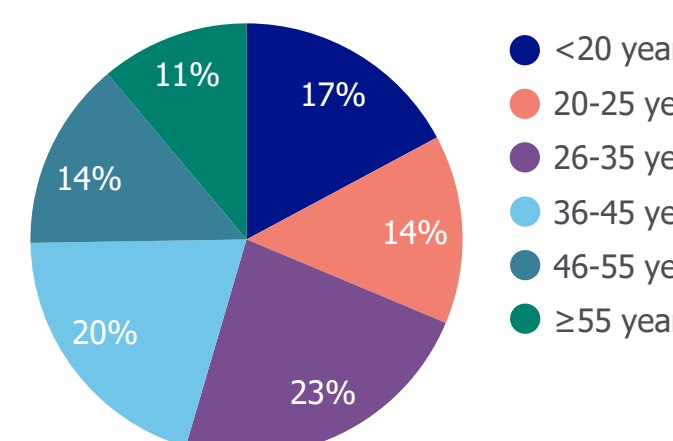
RESPONDENT DEMOGRAPHICS

- 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.

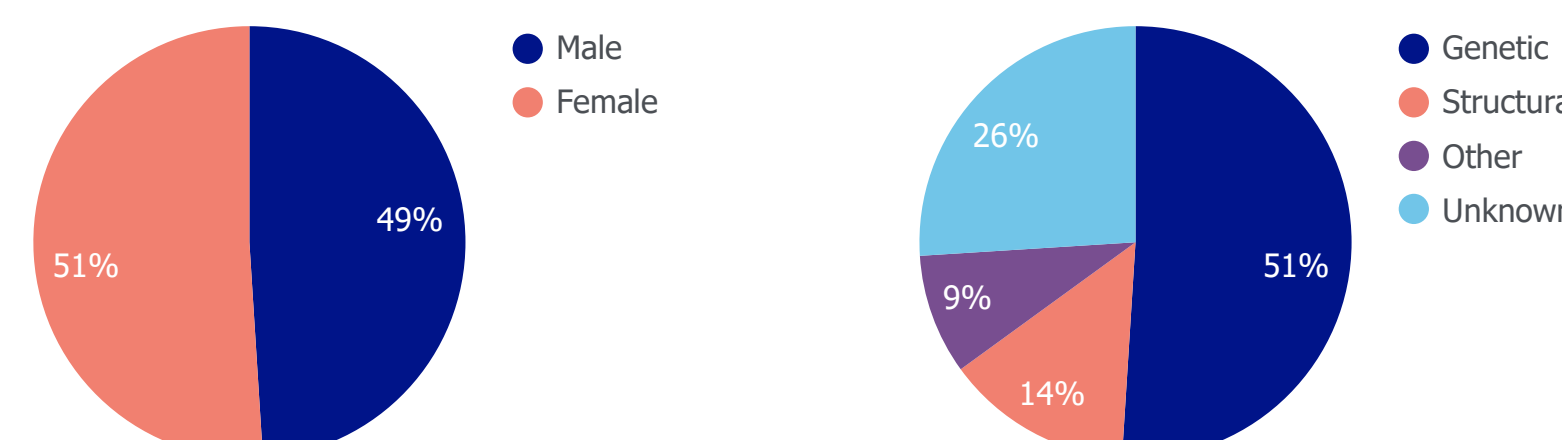
Participant type



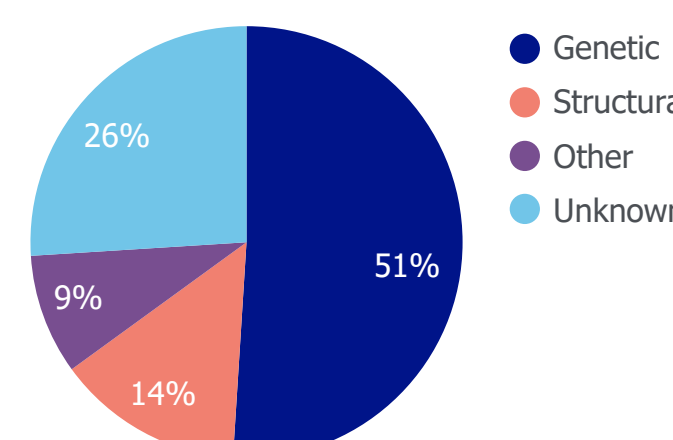
Age of PwE



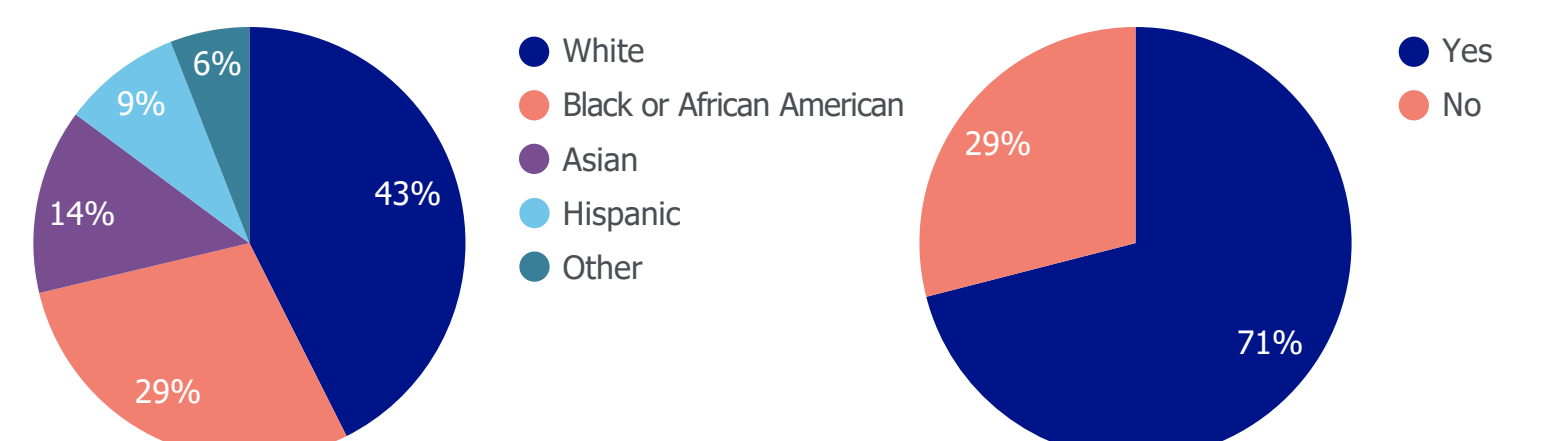
Sex of PwE



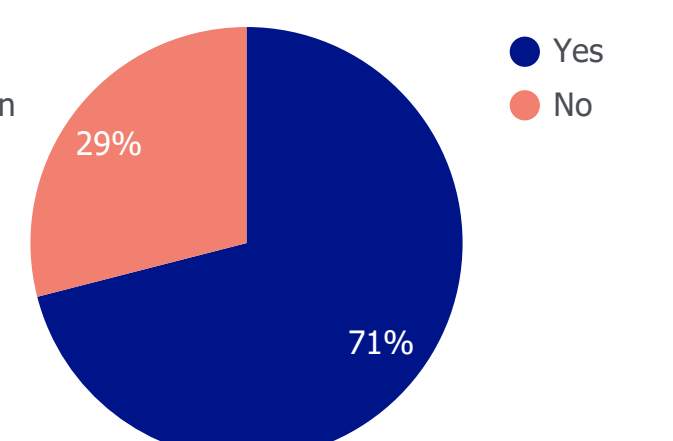
Cause of epilepsy^b



Ethnicity



Currently experiencing PS^b



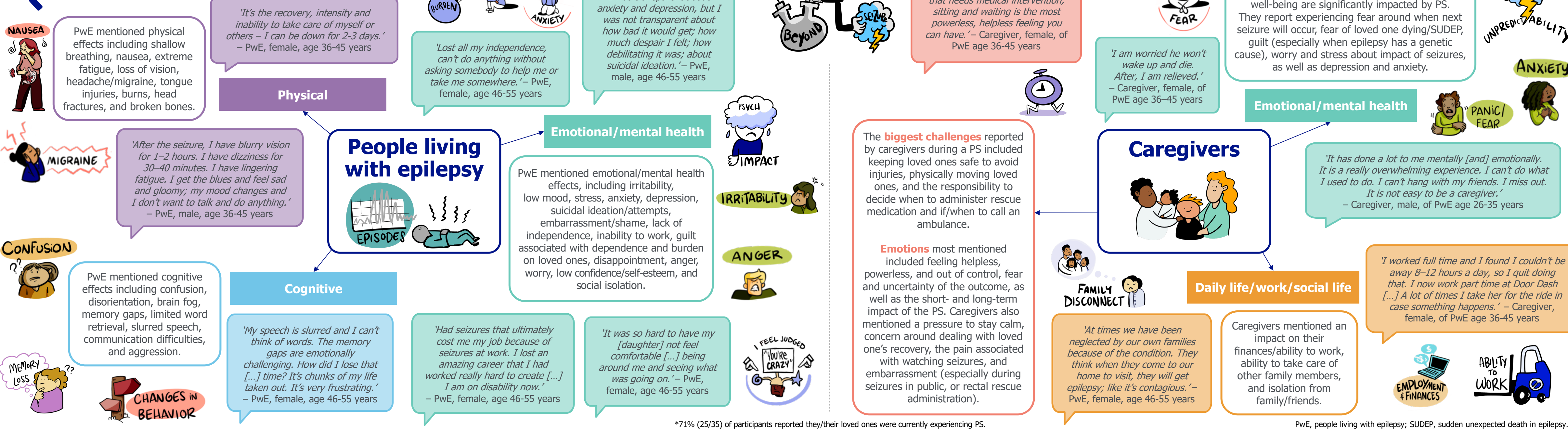
Due to rounding, percentages don't always add up to 100%. *Categorized as caregiver in analysis; ^bSelf-reported by participants. PS, prolonged seizures; PwE, people living with epilepsy.

Overview

QUESTION

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

RESULTS



CONCLUSIONS

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 psychological support for PwE and their families.

MENTAL HEALTH

- Mental health and emotional well-being were among the biggest challenges and concerns mentioned by PwE and caregivers in this study.

EMOTIONAL WELL-BEING & MENTAL HEALTH

90% of participants experienced



ANXIETY



60%



POST-ICTAL RECOVERY PERIOD

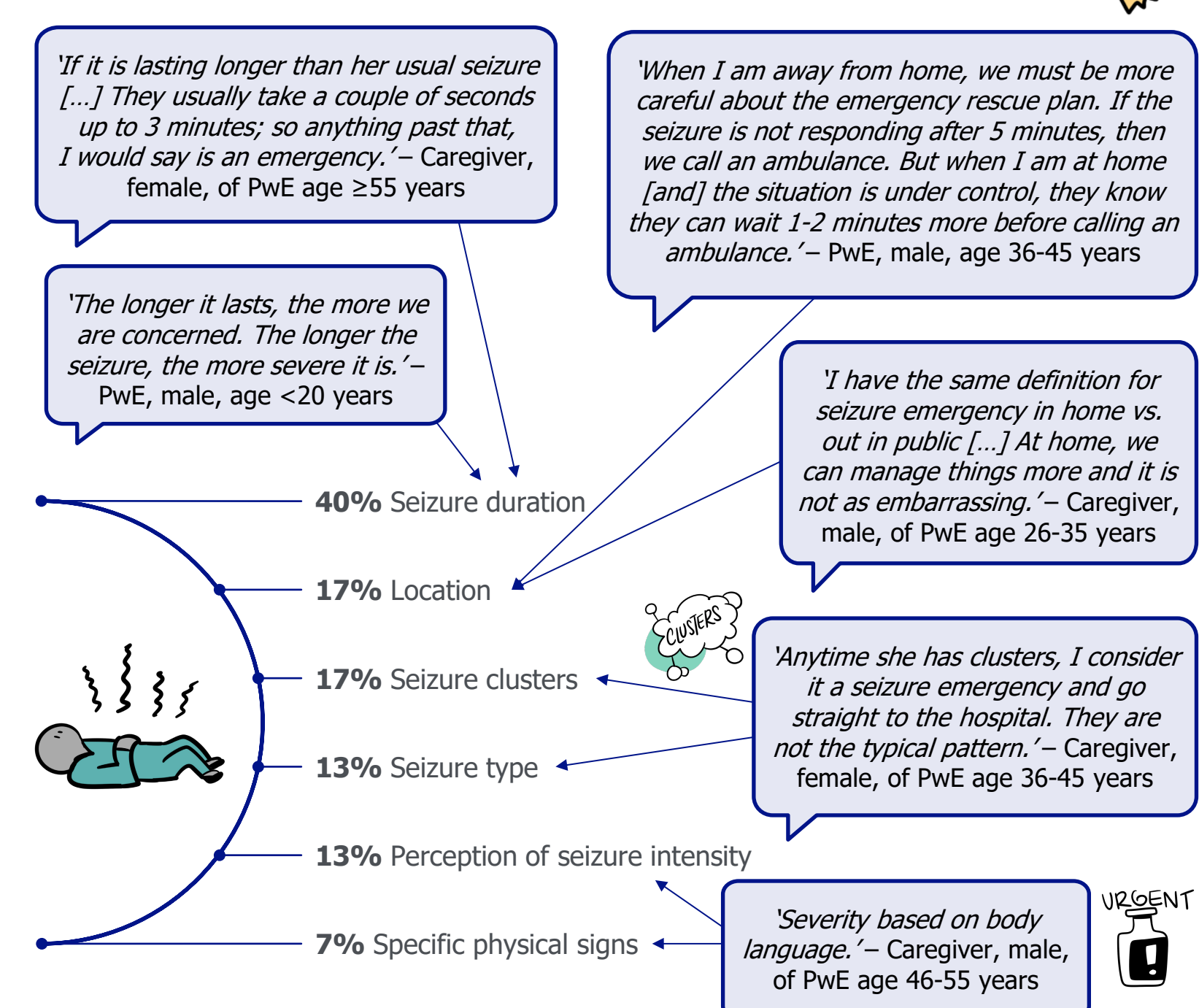
- PwE reported additional challenges with the PS post-ictal recovery period, including physical injuries, feeling weak or tired, and/or temporary inability to return to work or care for others.
- 83% (29/35) of participants correlated seizure duration with longer recovery time.
 - These PwE and caregivers found that recovery time could take up to 2 weeks if they had a seizure emergency that resulted in a hospital stay.
 - Even outside of hospitalization/emergency healthcare, these participants reported 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 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 well-controlled.

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WHAT IS THE MAIN DRIVER FOR INTERVENING DURING A SEIZURE?^a



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

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^a 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; ^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. Piña-Garza JE, et al. *Epileptic Disord* 2024;26(4):484-497. <https://doi.org/10.1002/epd2.20243>.

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