Poster P4-008

Loss of Productivity, Seizure Worry, and Patient and Caregiver Quality of Life Associated With Prolonged Seizures: Results From a Global Real-World Point-in-Time Study

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Background

- Patients with epilepsy have the constant uncertainty of experiencing a seizure, which could happen at any time, and this unpredictability can create fear and anxiety.[1]
- Seizure worry can deeply affect patients' mental health and quality of life, and lead to stigma and social isolation.[1]
- Seizures can become prolonged or progress in severity to impaired consciousness seizures with or without observable manifestations, convulsive seizures, seizure clusters, and status epilepticus.
  - Such seizures can be associated with loss of productivity and a lower quality of life.
- Given the uncertainty as to whether seizures will become prolonged or progress to a more severe seizure type, patients who experience prolonged seizures are very likely to worry about having a seizure.
- However, there remains a gap in the literature on prolonged seizures, and their impact on patients and caregivers is not well characterized.

Objective

- To describe loss of productivity, seizure worry, and quality of life associated with prolonged seizures among patients with epilepsy and their caregivers.

Methods

- Data were drawn from Adelphi's Prolonged Seizure Disease Specific Programme™ (DSP), a real-world point-in-time survey (RWE0807) conducted in China, France, Germany, Italy, Japan, Spain, the United Kingdom, and the United States between March 2023 and February 2024.
- Ethics approval was obtained from the Pearl Institutional Review Board.
- The DSP methodology has been previously described,[2,3] validated,[4] shown to be representative of the consulting population, and shown to be consistent over time.[5]
- A total of 308 neurologists, epileptologists, and internal medicine specialists completed patient record forms for 2454 consecutively consulting patients with prolonged seizures; patient characteristics, treatment usage, and healthcare resource utilization for the overall population have previously been presented.[6]
- The same patients and their caregivers were invited to voluntarily provide patient or caregiver self-completion forms, respectively (no self-completion forms were collected in the United Kingdom in this study).
- Here, we present the data from these self-completion forms that covered:
  - Work Productivity and Activity Impairment (WPAI) questionnaire;
  - Impact seizures have had on their life in the prior 3 months;
  - EuroQol 5-Dimensions, 5-Levels (EQ-5D-5L) questionnaire;
  - Patient-Weighted Quality of Life in Epilepsy (QOLIE-10-P version 2.0) questionnaire; and
  - Self-report of health conditions developing or worsening (caregivers only).
- Patients were eligible for inclusion if they were ≥12 years of age, were receiving a stable regimen of antiseizure medications, and had experienced ≥1 prolonged seizure in the prior 12 months.
- In this study, prolonged seizures were defined as any seizure lasting ≥2 minutes and/or longer than normal.
  - Non-prolonged seizures were defined as the patient's regular or normal seizures.
- The impact of prolonged and non-prolonged seizures on seizure worry, physical health, personal/home life, and mental health are presented for both prolonged and non-prolonged seizure events.

Results

DEMOGRAPHICS

- Among the 2454 patients with prolonged seizures assessed in this study, 515 patients and 286 caregivers provided self-completion forms.

Overview

QUESTION

What are the impacts of prolonged seizures on work productivity, seizure worry, and quality of life among patients with epilepsy and their caregivers?

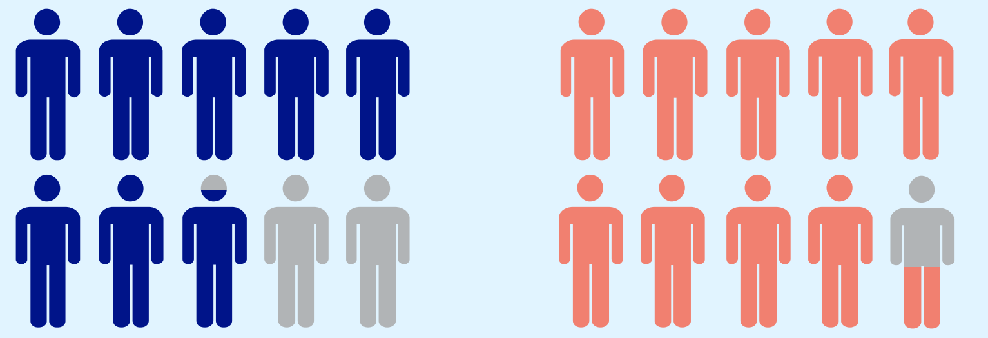
INVESTIGATION

Data were drawn from Adelphi's Prolonged Seizure Disease Specific Programme™, a real-world point-in-time survey. Neurologists, epileptologists, and internal medicine specialists completed patient record forms for patients with prolonged seizures. Patients and caregivers were invited to voluntarily provide self-completion forms.

RESULTS

Productivity loss

The proportion of patients and caregivers who reported that prolonged seizures affected work productivity in the prior 7 days

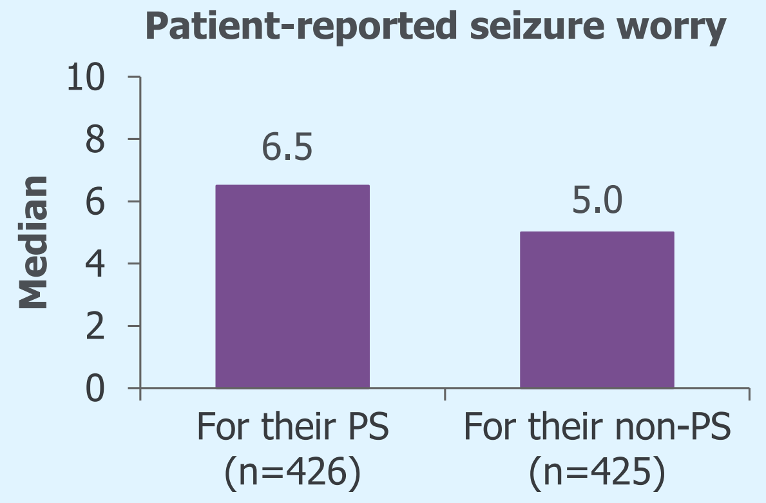


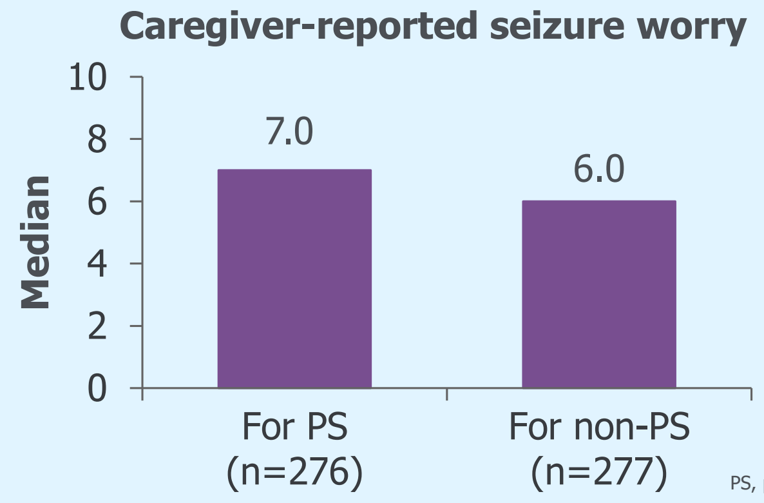
Patients: 79%
(n=181/229)

Caregivers: 94%
(n=157/167)

Seizure worry

Responses to worrying about when the next seizure will occur from 0 'does not worry me at all' to 10 'causes me to worry all the time' in the prior 3 months

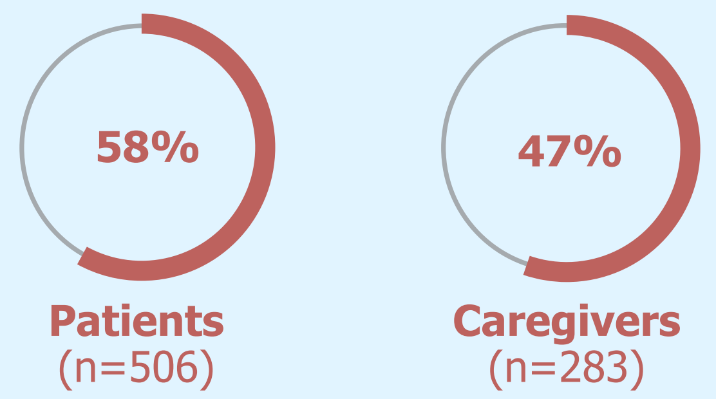




PS, prolonged seizure.

Reported anxiety or depression

Proportion of patients or caregivers of patients with prolonged seizures who reported being at least slightly anxious or depressed



CONCLUSIONS

Prolonged seizures affected patients' and their caregivers' work productivity and ability to perform normal daily activities. Patients and caregivers were more worried about the occurrence of the next prolonged seizure than the next non-prolonged seizure. Prolonged and non-prolonged seizures can have a negative impact on patients' and caregivers' mental health, with many reporting being at least slightly anxious or depressed. Caring for a patient with prolonged seizures can lead to the development or worsening of caregiver health conditions.[a]

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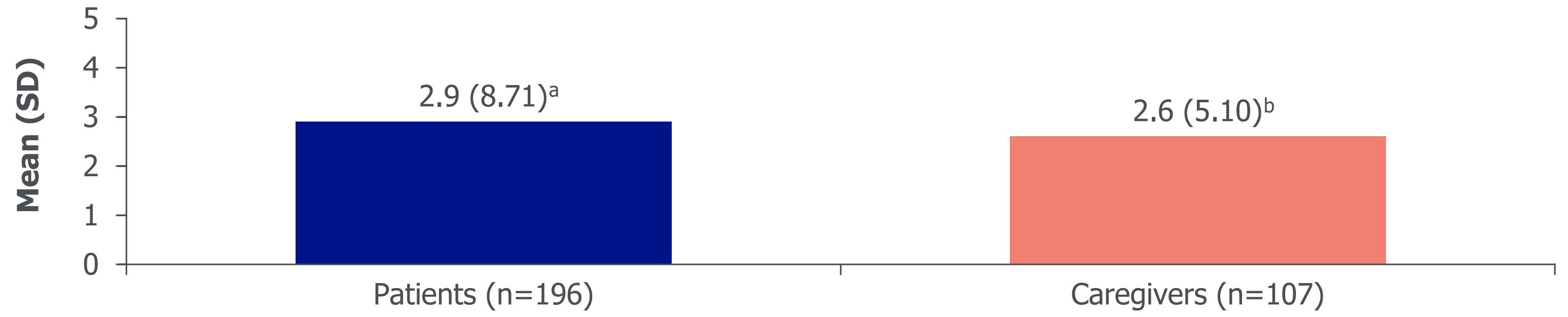
[a] Remaining results in the conclusions are shown in the main body of the poster.

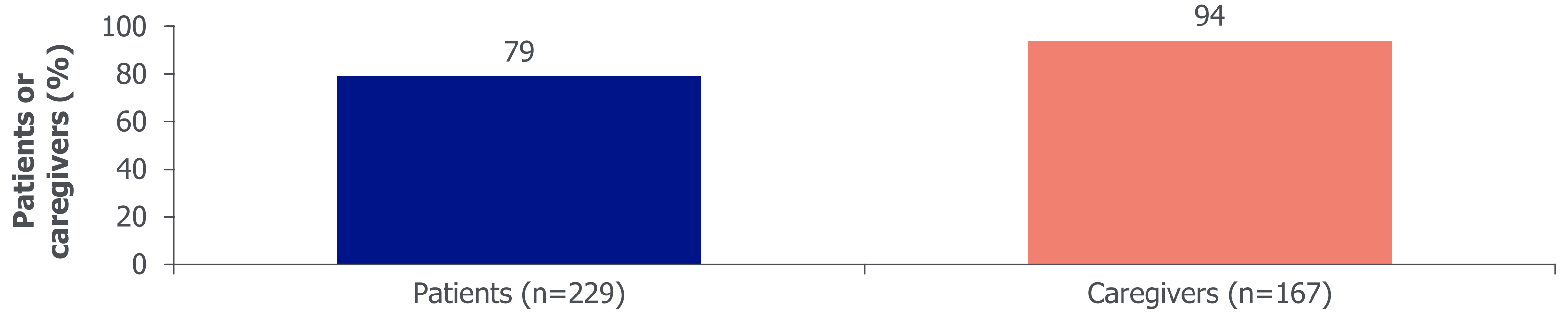
PRODUCTIVITY LOSS

Work hours missed



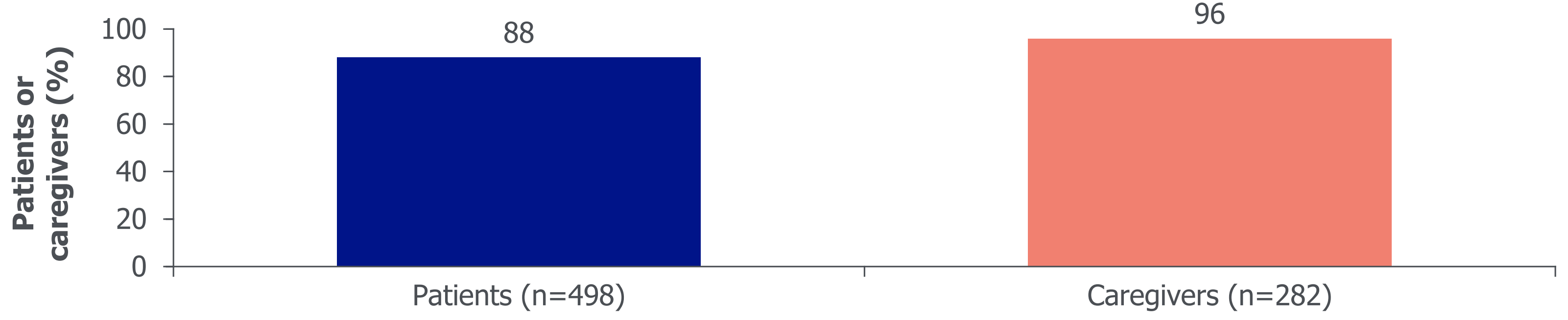
Patients and caregivers provided responses on how many hours they missed from work because of problems associated with their prolonged seizures (for patients) or because of caring for the patient with prolonged seizures (for caregivers) in the prior 7 days in the Work Productivity and Activity Impairment questionnaire. [a]Patients missed a median (Q1, Q3) of 0 (0, 2.0) work hours because of problems associated with their prolonged seizures; [b]Caregivers missed a median (Q1, Q3) of 0 (0, 4.0) work hours because of caring for the patient with prolonged seizures. Q1, 25th quartile; Q3, 75th quartile.

Work productivity affected



Patients and caregivers provided responses on how much their prolonged seizures (for patients) or caring for the patient with prolonged seizures (for caregivers) affected their productivity while they were working in the prior 7 days in the Work Productivity and Activity Impairment questionnaire. Responses were given on a scale from 0 'no effect on my work' to 10 'completely prevented me from working'. Results are the proportion of patients or caregivers providing a response from 1 to 10 (ie, at least some effect on work productivity).

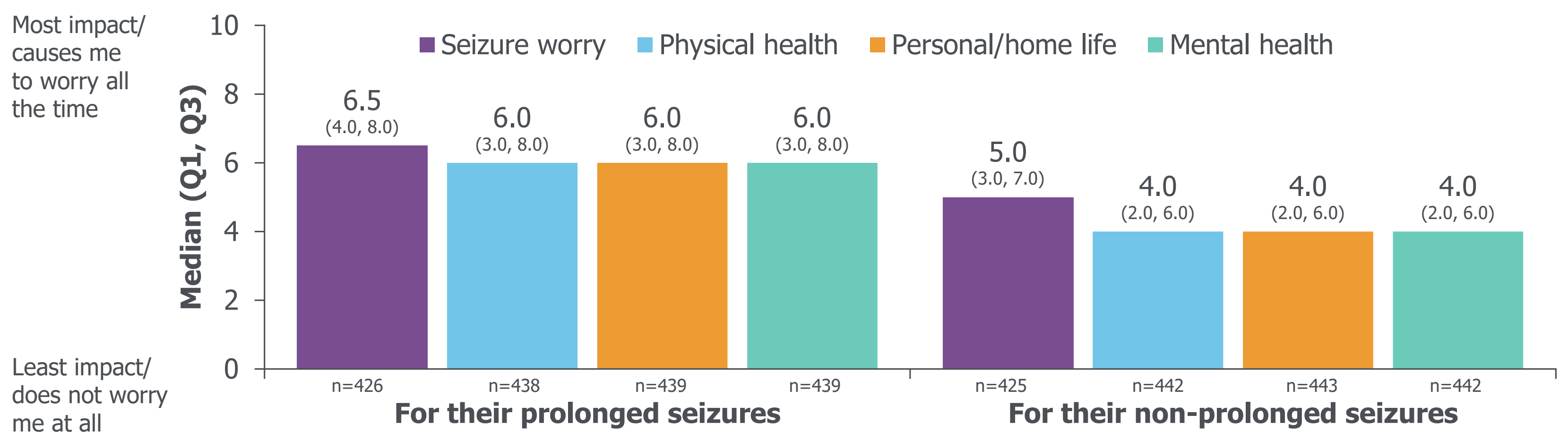
Ability to perform normal daily activities affected



Patients and caregivers provided responses on how much their prolonged seizures (for patients) or caring for the patient with prolonged seizures (for caregivers) affected their ability to perform normal daily activities in the prior 7 days in the Work Productivity and Activity Impairment questionnaire. Responses were given on a scale from 0 'no effect on my daily activities' to 10 'completely prevented me from doing my daily activities.' Results are the proportion of patients or caregivers providing a response from 1 to 10 (ie, at least some effect on daily activities).

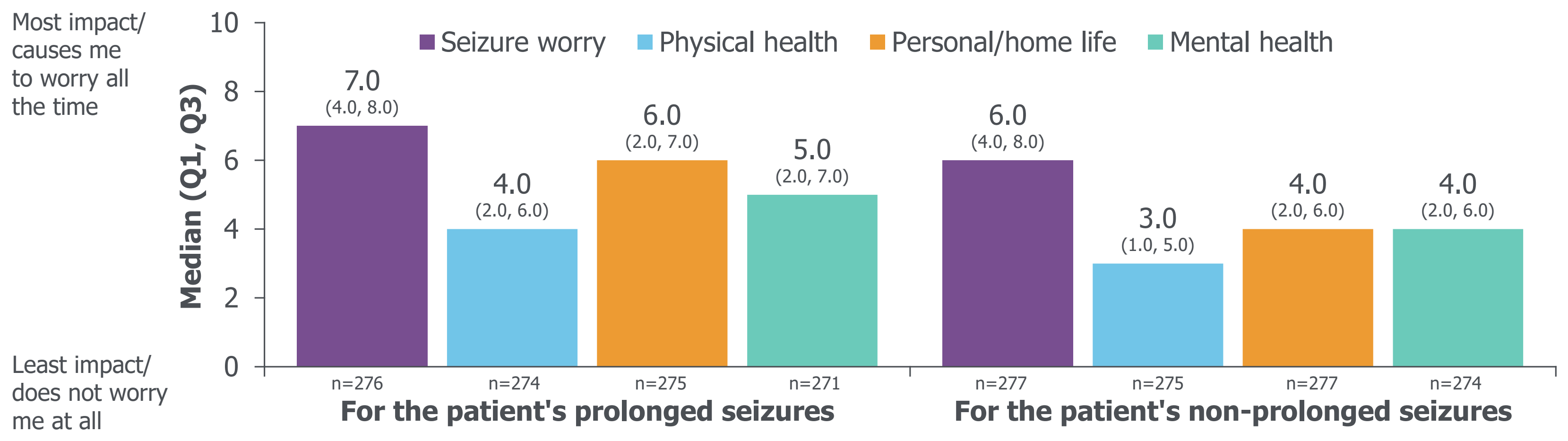
SEIZURE WORRY

Patient-reported impact of prolonged and non-prolonged seizures[a]



Patients with prolonged seizures self-reported how much of an impact prolonged and non-prolonged seizure events have had on their life in the prior 3 months by providing a number from 0 'does not worry me at all' to 10 'causes me to worry all the time' regarding worrying about when the next seizure will occur, and 0 'no impact' to 10 'most severe impact' for physical health, personal/home life, and mental health. [a]These data were presented previously at the 36th International Epilepsy Congress 2025.[6] Q1, 25th percentile; Q3, 75th percentile.

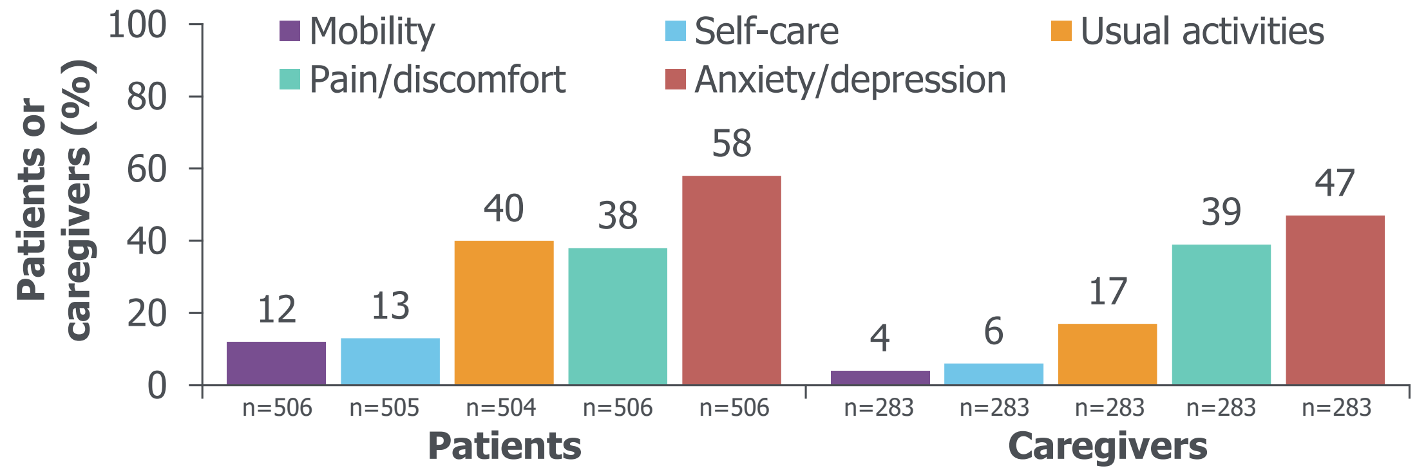
Caregiver-reported impact of prolonged and non-prolonged seizures



Caregivers of patients with prolonged seizures self-reported how much of an impact the patient's prolonged and non-prolonged seizure events have had on their life in the prior 3 months by providing a number from 0 'does not worry me at all' to 10 'causes me to worry all the time' regarding worrying about when the next seizure will occur, and 0 'no impact' to 10 'most severe impact' for physical health, personal/home life, and mental health. Q1, 25th percentile; Q3, 75th percentile.

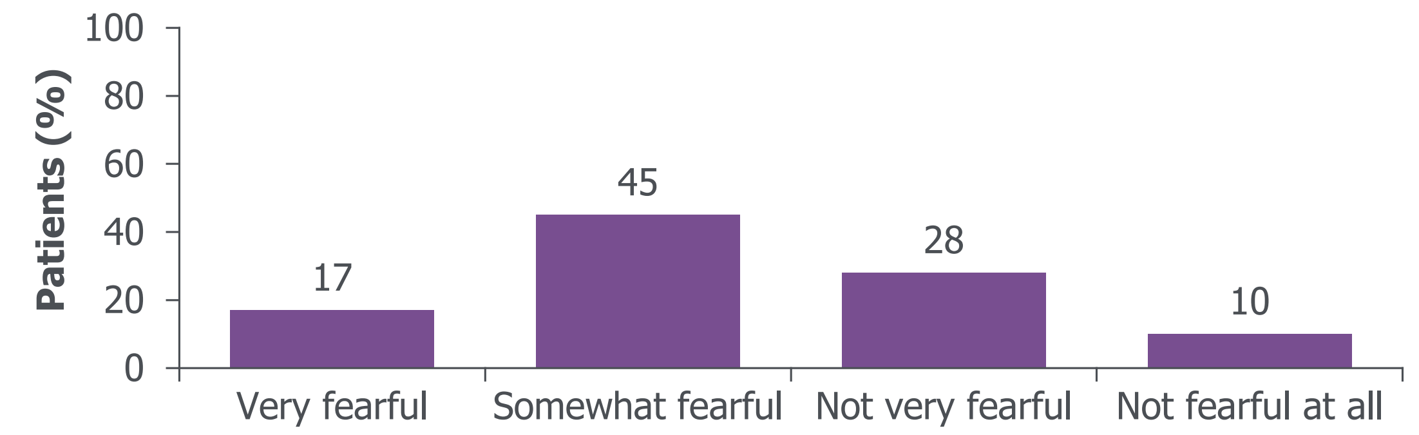
QUALITY OF LIFE

Patients or caregivers reporting at least slight health problems



Based on patients and caregivers of patients with prolonged seizures self-reporting on their current health state in the EQ-5D-5L questionnaire. EQ-5D-5L, EuroQol 5-Dimensions, 5-Levels.

Patient's fear of having a seizure during the next 4 weeks



Based on patients with prolonged seizures self-reporting on how afraid they were of having a seizure during the next 4 weeks in the QOLIE-31-P questionnaire (question 9; n=505). QOLIE-31-P, Patient-Weighted Quality of Life in Epilepsy.

Health conditions developing or worsening in caregivers

- 24% of caregivers (n=62/263) reported a health condition developing or worsening due to caring for a patient with prolonged seizures.
  - The most common (≥5%) health conditions developing or worsening were sleeping problems (10%) and anxiety (9%).

Conclusions

- Prolonged seizures affected patients' and their caregivers' work productivity and ability to perform normal daily activities.
- Patients and caregivers were more worried about the occurrence of the next prolonged seizure than the next non-prolonged seizure.
- Prolonged and non-prolonged seizures can have a negative impact on patients' and caregivers' mental health, with many reporting being at least slightly anxious or depressed.
- Caring for a patient with prolonged seizures can lead to the development or worsening of caregiver health conditions.

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