

# Epilepsy Monitoring of Prospective Seizure Observations with Electronic Records (EMPOWER): An Observational Study Designed to Better Understand the Patient Journey



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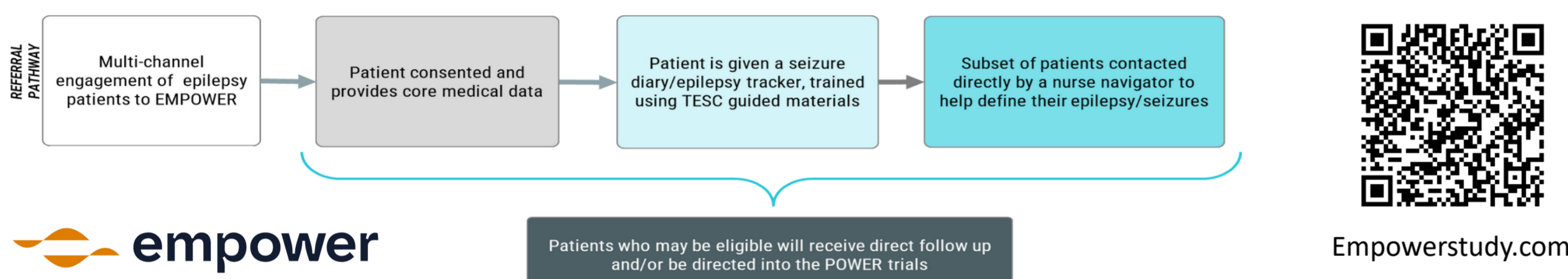
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## Background

- Epilepsy is a complex neurological disease characterized by unprovoked, spontaneous seizures.
- There are ~50 million affected individuals worldwide, with a significant number experiencing uncontrolled seizures despite antiseizure medications (ASMs).
- Associated with this is decreased quality of life and increased risk of overall mortality from sudden unexpected death in epilepsy (SUDEP) and seizure-related accidents.
- EMPOWER is an ongoing study led by Praxis Precision Medicines, in partnership with the Epilepsy Study Consortium, which aims to characterize seizure burden and antiseizure medication (ASM) use patterns over time in patients with a confirmed epilepsy diagnosis; empowering them to actively participate in their epilepsy journey; and help identify subjects for Praxis clinical trials.

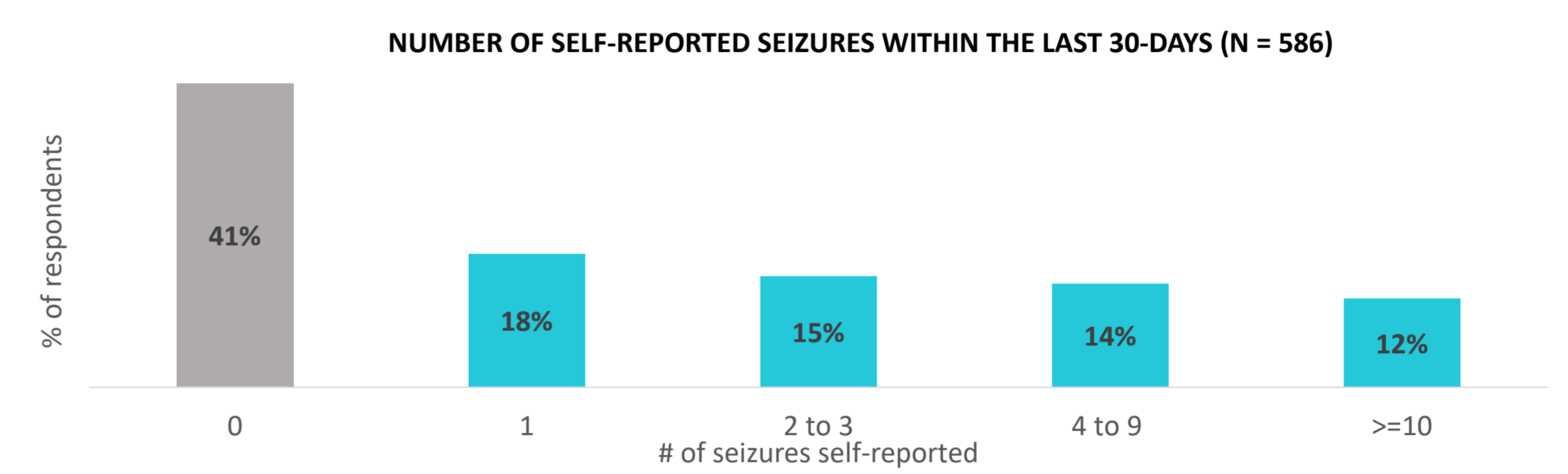
## Methods

- EMPOWER aims to recruit US participants aged ≥18 years with a confirmed epilepsy diagnosis.
- Participants who elect to enroll are followed for a prospective observational period of up to 24 months.
- EMPOWER includes a survey across 4 main areas: epilepsy history; current seizure experience; seizure tracking; personal information (e.g., age, gender, etc.)
- Eligible participants will access an electronic seizure diary to record seizures and ASM use.
- Participants opting to share medical records will have linked records capturing seizure-related disease course, and prospectively tracking intercurrent events (e.g. hospitalizations, infections).
- Study surveys will collect information including demographics, seizure types/counts and seizure tracking behavior.
- Periodically, summarized deidentified reports will be shared with participants to facilitate learning from others' experiences.
- Data are presented from 586 respondents that have been surveyed prior to referring to a clinical study.



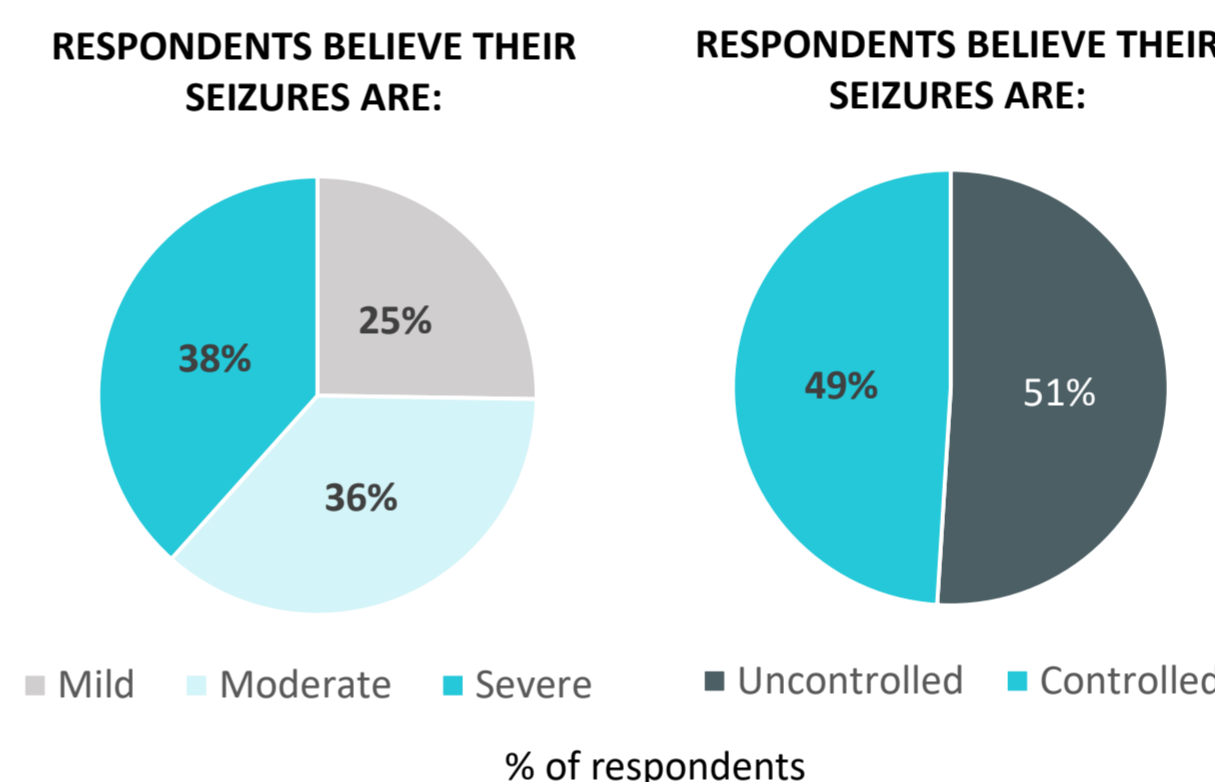
## Seizure Experience & Antiseizure Medication Use

Nearly 60% of respondents experienced seizures in the last month



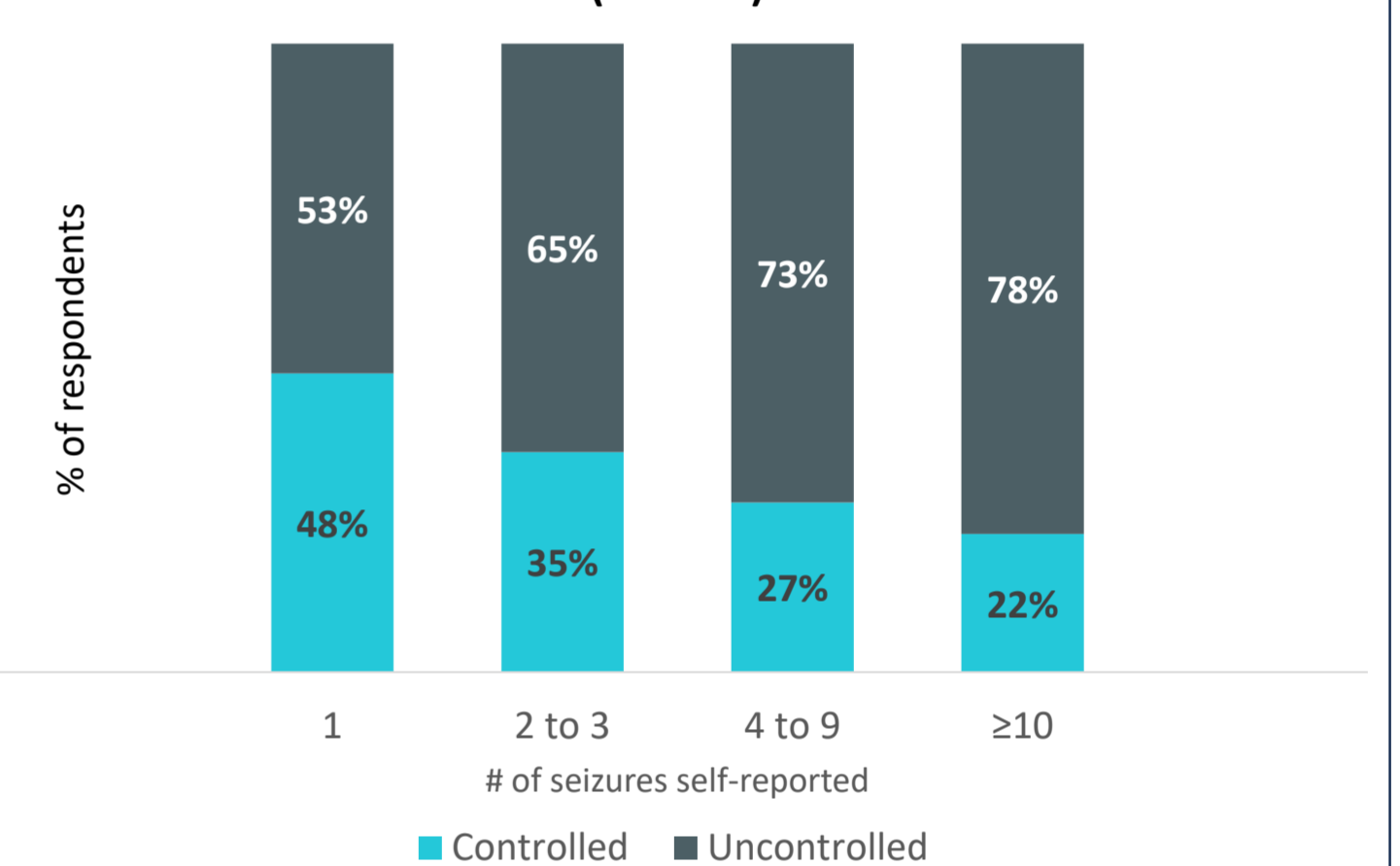
More than 3/4 reported their seizures as moderate to severe, with almost half believing they are uncontrolled

SELF REPORTED SEIZURE DESCRIPTION (N=586)



Half of patients reporting a single seizure within the last 30-days believe they are uncontrolled

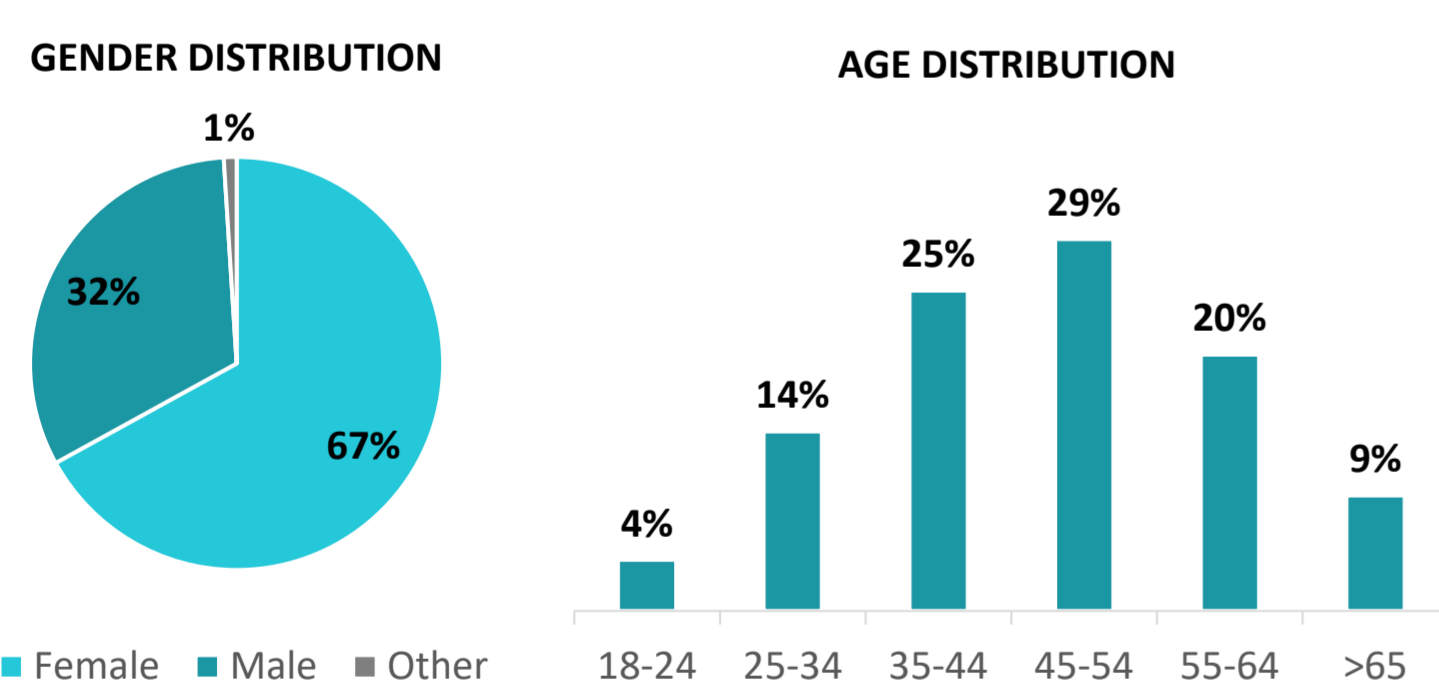
SEIZURE FREQUENCY LAST 1 MONTH (N = 345)



## Key Demographics

67% of respondents are female, and most are between the ages of 35 and 54

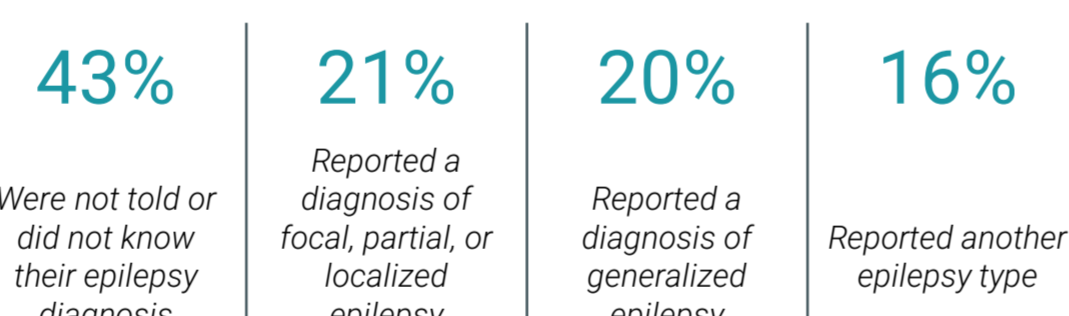
EMPOWER RESPONDENT DEMOGRAPHICS (N = 586)



Less than 10% of patients reported being managed by an epileptologist



Most participants indicated they are unaware of their epilepsy type

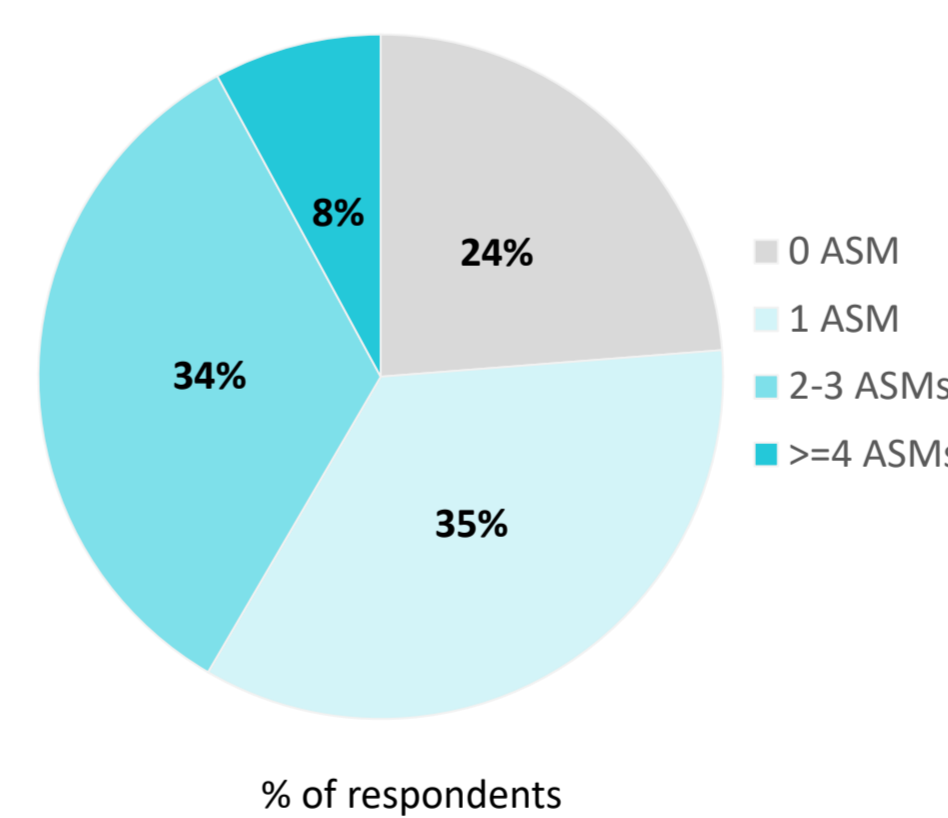


\*PCP: Primary Care Provider

## Seizure Descriptions & Impact on Quality of Life

Despite currently available ASMs, respondents self-report continued seizures they describe as both uncontrolled and moderate to severe – even while on multiple medications – with greater impact on quality of life among those reporting higher ASM counts

SELF REPORTED ASM COUNT (N=586)

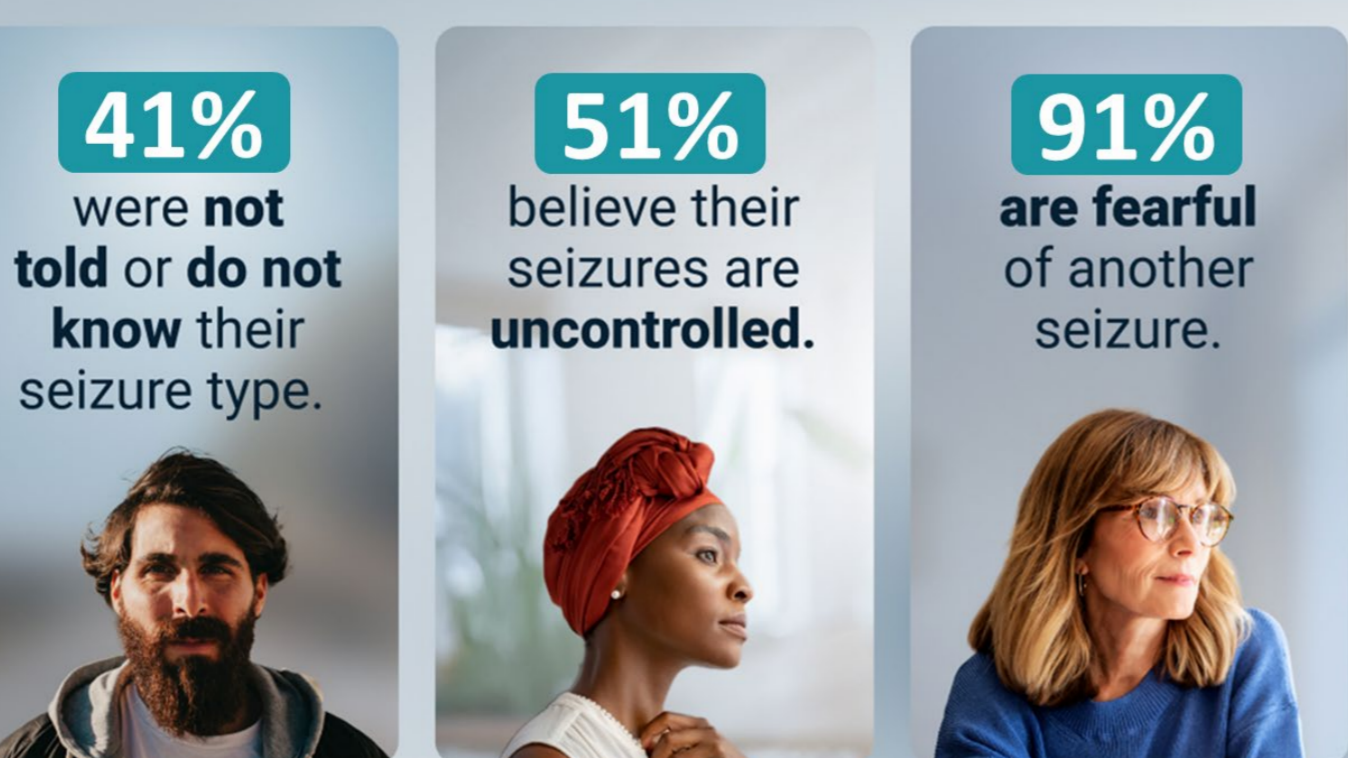


# of self reported ASMs	% of respondents experiencing seizures	Among Patients Reporting Seizures (30-day)	
		Mean 30-day seizure count	Median 30-day seizure count
0 ASMs (n = 139)	43%	1.6	3
1 ASM (n = 202)	58%	2.0	3
2-3 ASMs (n = 208)	65%	2.2	3
≥4 ASMs (n = 37)	86%	3.2	5

## Conclusion

- The EMPOWER observational study, in partnership with the Epilepsy Study Consortium, is ongoing and continues to generate standardized, longitudinal data to support planned interventional trials and deepen understanding of patient experiences of epilepsy.
- Findings from the first ~500 patients reveal that few patients are cared for by epileptologists, with epilepsy patient burden compounded by uncontrolled seizures that affect quality of life.
- Despite being on multiple ASMs, patients continue to report seizures, reinforcing the urgent need for targeted and innovative therapies.

These are the voices of the first 500 patients who shared their epilepsy experience in the EMPOWER study:



SELF REPORTED IMPACT ON QUALITY OF LIFE BY ASM COUNT (N=586)

Quality of Life Attribute	Overall (N=586)	≥4 ASMs (n=37)	2-3 ASMs (n=202)	1 ASM (n=208)	0 ASM (n=139)
Inability to work or study	54%	62%	61%	51%	46%
Mental Effects of ASMs	46%	64%	49%	37%	41%
Physical Effects of ASMs	43%	62%	43%	32%	31%
Social Limitations	42%	60%	54%	41%	40%
Medication Burden	38%	65%	47%	40%	37%

Heat map depiction of the % of respondents who perceive considerable to significant quality of life impact on the metrics listed (4 or 5 on 5-point scale)

Increasing severity →

## References

- GBD 2021 Global Prevalence Data Lancet Public Health
- WHO 2023 Epilepsy Fact Sheet
- Gupta et al 2017 Epilepsia Open
- Seiden & Connor 2022 Epilepsy & Behavior

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