

# Effects of Insurance Coverage and Antiseizure Medication Formulary Policies on the Experiences of Patients With Epilepsy and Healthcare Professionals: A Qualitative Study

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## Background

- Previous studies have indicated that treatment of epilepsy varies by insurance type (private vs. public),<sup>1</sup> whilst others have shown little disparity across insurance types.<sup>2</sup>
- Scant information is available regarding the impact of insurance coverage and antiseizure medication (ASM) formulary policies on the management of patients with epilepsy (PWE).

## Objective

- To understand the impact of insurance coverage and ASM formulary policies on stakeholder experiences related to disease management and perceptions of care, ASM initiation, ASM access and affordability, and ASM adherence and abandonment.

## Methods

### QUALITATIVE INTERVIEWS

- Qualitative interviews were conducted with healthcare professionals (HCPs) and non-HCPs between January 13, 2023 and February 17, 2023.
  - HCP interviews lasted 60 minutes and included primary care physicians (PCPs), neurologists, epileptologists, and pharmacists.
  - Non-HCP interviews lasted 30 minutes and included PWE, caregivers of PWE, and patient advocates.
- Interview transcripts were assessed with a content analysis approach to identify key themes and insights.
- The geographic scope of this study covers the United States, and included urban, rural, and suburban designations.

## Results

### HCP RESPONDENT CHARACTERISTICS

- PCPs (n=15), neurologists (n=10), and epileptologists (n=5) spent an average of 11, 12, and 15 years, respectively, in practice and had 151, 586, and 617 patients with epilepsy, respectively, under their care.
  - Practice settings considered were urban, suburban, and rural for 33%, 60%, and 7% of PCP practices, respectively, whereas urban and suburban areas were reported by 70% and 30% of neurologist practices and 80% and 20% of epileptologist practices.
- Pharmacists worked in national retail chains (n=3), hospital pharmacies (n=2), or stand-alone independent pharmacies (n=5), with a mean of 12, 12.5, and 16 years in practice, respectively.
  - 30%, 40%, and 30% of pharmacist practices were in urban, suburban, and rural areas, respectively.

### Physician epilepsy population by insurance type (% of patients)<sup>a</sup>

Insurance type	PCPs	NEUROLOGISTS	EPILEPTOLOGISTS
Medicare	23%	24%	28%
Medicaid	26%	30%	30%
Commercial/private	37%	36%	36%
Tricare/other military	4%	6%	2%
Health insurance plan through ACA marketplace	5%	4%	3%
No insurance/uninsured	5%	1%	1%

<sup>a</sup>Epilepsy Discussion Guide (Neurologists and PCPs) question: "How would you describe the demographics of your epilepsy patients as it relates to their age, sex, race, and insurance mix?"  
 ACA, Affordable Care Act; PCP, primary care physician.

### NON-HCP RESPONDENT CHARACTERISTICS

- Patient respondents (n=13) had a mean age of 41 years, were diagnosed at a mean of 26 years, and had a mean epilepsy duration of 17 years.
- Insurance types amongst patients were Commercial (n=5), Medicare and Medicaid (n=3), Medicaid only (n=2), Medicare only (n=2), and Affordable Care Act Marketplace (n=1).
  - Amongst caregivers (n=6), insurance types were Commercial (n=3) and Medicaid (n=3).
- Patient advocates (n=6) were either program directors (n=5) or case managers (n=1).

## Overview

### QUESTION

What is the impact of insurance type and antiseizure medication (ASM) formulary policies on stakeholder experiences related to disease management and ASM initiation, access, affordability, and adherence?

### INVESTIGATION

Qualitative interviews, conducted between January and February 2023 in the United States, were assessed with a content analysis approach to highlight key themes and insights. Healthcare professionals (HCPs) interviewed included primary care physicians (PCPs), neurologists, epileptologists, and pharmacists. Non-HCPs interviewed included patients with epilepsy, caregivers, and patient advocates.

### RESULTS

#### Types of HCP and non-HCP survey participants

#### Challenges for patients with epilepsy

- WAITLISTS:** Specialist shortage → Long wait times (several months)
- GEOGRAPHY:** Rural patients → Long travel distance for specialized care
- MEDICAID:** Some practices → Limited or no Medicaid acceptance
- TELEHEALTH:** Telemedicine limited → Lower reimbursement rates

#### Challenges for HCPs treating epilepsy

- Primary Care Physicians:** High reliance on PCP-directed care for ASM refills and ongoing management. Lack training, time, and resources to navigate insurance appeals process.
- Neurologists/Epileptologists:** Specialists invest time appealing insurance rejections, which can take up to 3-6 weeks. This is a frustrating process.

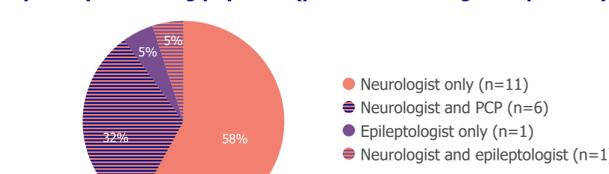
### CONCLUSIONS

Insights from the study indicate a need for: 1) education and support for PCPs to manage more complex cases with newer ASMs; 2) support for PCPs in navigating the insurance approval process; 3) improvements in patient access to specialists; 4) support for Medicaid patients such as access to programs that connect them with specialists, patient advocacy programs, and financial assistance.

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### Specialty of treating physician (patients and caregivers' patients)



- All interviewed patients and caregivers' patients were being seen by a neurologist for treatment of their epilepsy.
- No patients were being seen by a PCP only.

### HCP ROLES

- Primary Care Physicians:**
  - Play an outsized role in the care of patients with epilepsy, particularly for medication refills and ongoing management.
  - Comfortable treating straightforward cases and prescribing older (1<sup>st</sup>/2<sup>nd</sup> generation) ASMs.
- Neurologists/Epileptologists:**
  - Diagnose epilepsy and treat complex cases.
  - Most often prescribes the initial ASM.
  - Associated with long wait times driven by a shortage of specialists.

- Pharmacists:**
  - Notify HCPs of insurance requirements, but do not navigate the insurance approval process.
- Patient Advocates:**
  - Help patients with transport and copy assistance for ASMs (via bridge programs, pharma companies, or charitable organizations).

### PATIENTS AND CAREGIVERS

- Of patient and caregivers providing a response, 100% (n=15) reported positive relationships with the HCP managing epilepsy care; patients/caregivers provided a mean satisfaction rating with current treatment as 5.7 out of 7 (=extremely satisfied).
- Most patients are highly adherent with taking their medications. Those labelled as non-adherent tend to be elderly or have psychiatric disorders.
- Patients face many barriers accessing specialist care:

#### WAITLISTS

Patients can face long wait times of several months. These wait times tend to be driven by a shortage of neurologists.

#### MEDICAID

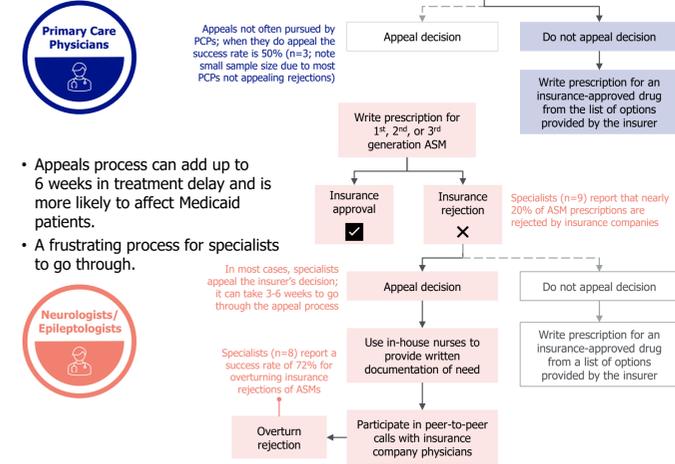
PCPs in this study share that some local neurology practices accept few to no Medicaid-insured patients, leaving this patient population to forego specialist care or travel long distances to see a neurologist who will accept their insurance.

#### TELEHEALTH

Virtual visits gained momentum during the COVID-19 pandemic and telehealth continues to ease travel burden for patients; however, some specialists say their networks now limit telemedicine visits as these are reimbursed at a lower rate than in-person visits.

### INSURANCE APPROVAL PROCESS

- PCPs and specialists handle insurance rejections very differently in terms of investment in the appeals process.
- PCPs lack training, time, and resources to navigate the insurance appeals process, and often avoid prescribing newer ASMs as a result.



- Appeals process can add up to 6 weeks in treatment delay and is more likely to affect Medicaid patients.
- A frustrating process for specialists to go through.

### CHALLENGES FOR MEDICARE/MEDICAID PATIENTS

- Many HCPs (n=21) reported that patients insured with Medicare/Medicaid have more difficulty accessing ASMs.
- Medicaid patients are more likely to experience treatment delays and have fewer treatment options compared with commercially-insured patients:



#### Access to fewer specialists

Not all specialists accept Medicaid. Patients with this insurance have less choice in the specialists they can see.

*'I would say people who have private insurances that are a little more reliable are typically able to get in to see someone [a neurologist] a lot sooner, and those that have, for example, Medicaid or sort of lower-tier insurance plan, they sometimes may have trouble to get into an office. Not all the offices, obviously, but some of the offices are pretty selective on which payers they accept.'* – PCP



#### Treatment delays

Limited or delayed access to specialists means Medicaid patients are more likely to experience delays to ASM initiation or specialist-driven treatment changes.

*'Medication-wise, I think commercial probably they can get the medications sooner. I mean for those medications we need prior authorization, probably they can get those medications sooner, and for Medicaid, probably it takes us a longer time, sometimes 2 weeks or even 1 month later [for patients to get their meds].'* – PCP



#### Fewer treatment options

High drug costs and lack of formulary coverage means newer branded ASMs are often not available for Medicaid patients.

*'For most of the state [Medicaid] patients that I see, there are likely fewer options and more prior auths [authorizations]. For the Medicare, of course there's a lot of different versions of Medicare, supplemental plans and Advantage plans, but it's pretty similar to commercial as far as Medicare.'* – PCP

## Conclusions

- This study identified challenges and insights among PWE and HCPs in managing epilepsy treatment.
- PCPs would benefit from education and support to manage more complex cases with newer ASMs and to navigate the insurance approval process.
- Improved patient access to specialists is needed.
- Medicaid patients would benefit from programs that connect them with specialists, patient advocacy programs, and financial assistance to help address barriers to epilepsy care.

## References

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- Thurman DJ, et al. *Epilepsy Res.* 2019;157:106210.

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