Access Barriers to Antiseizure Medications and Neurologists: Effects on Epilepsy Stakeholder Experiences

Herbert Peeples[1]
Emily Achter[2]
Christopher Dieyi[2]
Danielle Drayton[3]
David Holman[3]
Keshia Maughn[2]

1. UCB Pharma, Smyrna, GA, USA
2. STATinMED, LLC, Dallas, TX, USA
3. REACH Market Research, Newton, MA, USA

Background

- Patients with epilepsy may not receive the antiseizure medications (ASMs) they need due to insurance restrictions[1,2] and limited access to neurology healthcare professionals (HCPs).[3]

Objective

- To understand the impact of insurer access restrictions on stakeholder experiences of epilepsy-related care and treatment.

Methods

QUANTITATIVE STUDY

- This retrospective longitudinal study identified adults in RWD Insights (an all-payer claims database) with ≥1 epilepsy diagnosis (*International Classification of Diseases [ICD]-9-Clinical Modification [CM]* codes: 345.4, 345.40, 345.41, 345.5, 345.50, 345.51, 345.7, 345.70, 345.71; *ICD-10-CM* codes: G40.0, G40.1, G40.2, G40.5) or ≥2 diagnoses for unspecified convulsions on different days (within 12 months) between January 1, 2014, and May 31, 2021.
  - Patients insured with Medicaid, Commercial, or Medicare healthcare insurance, prescribed ≥1 ASM on or after initial diagnosis (first ASM date = index date) with continuous medical and pharmacy benefits for ≥12 months pre-index and post-index (follow-up).
  - Outcomes: ASM use/restrictions, proximity (ZIP3 code) to/use of neurology HCP for epilepsy-related care; healthcare resource use (HCRU)/costs post-index. Epilepsy-related medical claims were identified by having an *ICD-9/10-CM* code for epilepsy in any position or Healthcare Common Procedure Code for an ASM. Pharmacy claims were epilepsy-related if patients had a National Drug Code for an ASM.
  - For epilepsy-related post-index HCRU and costs (in 2021 US dollars), patients were stratified by number of third-generation ASMs with access restrictions (prior authorization/step therapy [range: 0-4]).

QUALITATIVE STUDY

- Stakeholder experiences were captured in qualitative interviews with HCPs and non-HCPs between January 13, 2023, and February 17, 2023.
  - 60-minute HCP interviews: primary care physicians, neurologists, epileptologists, and pharmacists.
  - 30-minute non-HCP interviews: patients with epilepsy, caregivers, and patient advocates.
- Interview transcripts were assessed with a content analysis approach to identify key themes/insights.

Overview

QUESTION

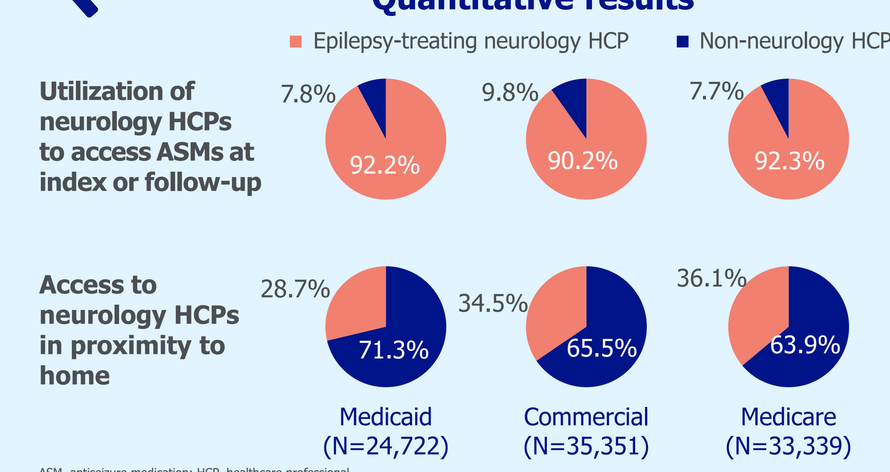
What is the impact of insurer access restrictions on stakeholder experiences of epilepsy-related care and treatment?

INVESTIGATION

- Retrospective, longitudinal, observational study that used real-world data from the all-payer claims database to capture patient characteristics, proximity from a neurology healthcare professional (HCP), and utilization of neurology HCPs to prescribe antiseizure medication (ASM) treatment for 12 months after first ASM prescription.
- Qualitative interviews were conducted in the United States (January and February 2023) and responses analyzed to highlight key themes and insights. Interviews were conducted with HCPs (primary care physicians, neurologists, epileptologists, and pharmacists) and non-HCPs (patients with epilepsy, caregivers, and patient advocates).

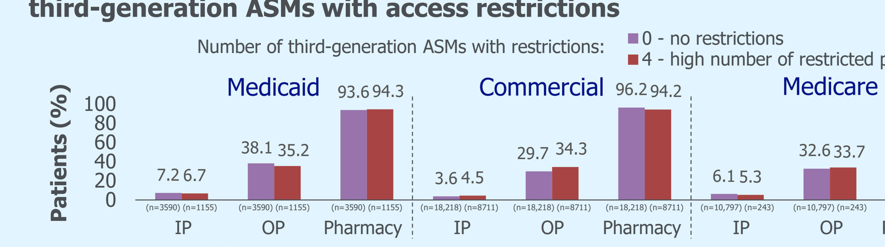
RESULTS

Quantitative results



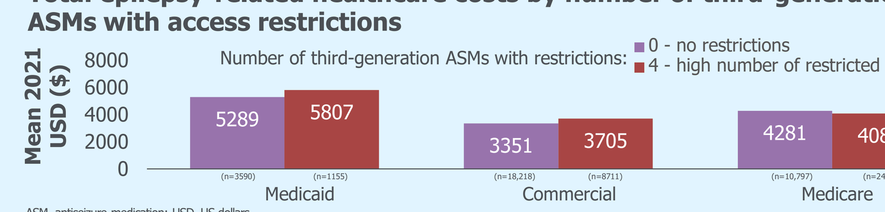
ASM, antiseizure medication; HCP, healthcare professional.

Percentage of patients with epilepsy-related HCRU by number of third-generation ASMs with access restrictions



ASM, antiseizure medication; HCRU, healthcare resource use; IP, inpatient; OP, outpatient.

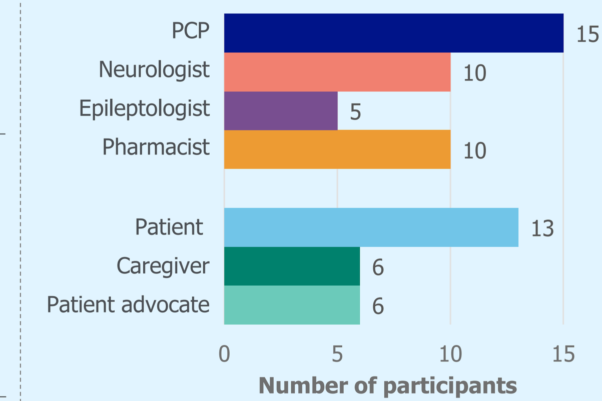
Total epilepsy-related healthcare costs by number of third-generation ASMs with access restrictions



ASM, antiseizure medication; USD, US dollars.

Qualitative 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 neurology practices ↓ Limited or no Medicaid acceptance
- **TELEHEALTH** Telemedicine limited ↓ Lower reimbursement rates

Challenges for HCPs treating epilepsy

Primary care physicians
- High reliance on physician-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 6 weeks. This is a frustrating process.

↓ = Arrow indicates leads/contributes to.
HCP, healthcare professional; PCP, primary care physician.

CONCLUSIONS

- Claims data revealed limited neurologist access and predominant use of second-generation ASMs but no notable impact of ASM access restrictions on healthcare resource use and costs.
- Ideally, ASM selection is based on optimizing individual outcomes rather than minimizing restrictions/denials; however, interviews revealed barriers to optimizing treatment and accessing specialty care.

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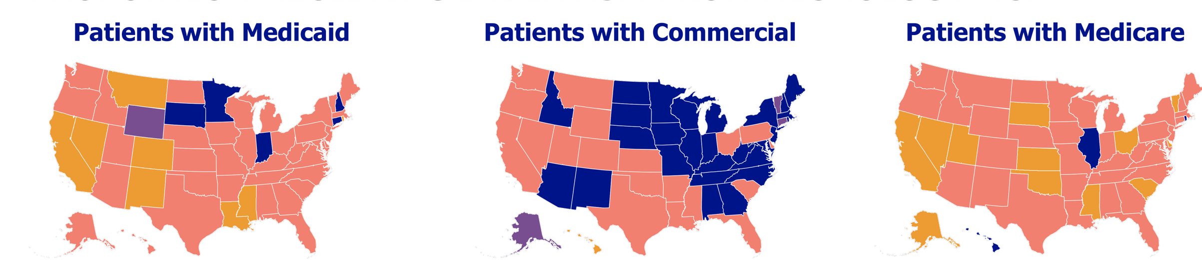
Quantitative study results

Patient baseline characteristics

	MEDICAID (N=24,722)	COMMERCIAL (N=35,351)	MEDICARE (N=33,339)
Age, mean (SD), years	43.3 (13.2)	47.5 (13.7)	72.8 (8.2)
Female, n (%)	15,419 (62.4)	20,928 (59.2)	14,765 (44.3)
Charlson Comorbidity Index Score, n (%)			
0	10,888 (44.0)	17,109 (48.4)	5865 (17.6)
1-2	7176 (29.0)	9589 (27.1)	9584 (28.7)
3-4	3582 (14.5)	4517 (12.8)	7642 (22.9)
>4	3076 (12.4)	4136 (11.7)	10,248 (30.7)

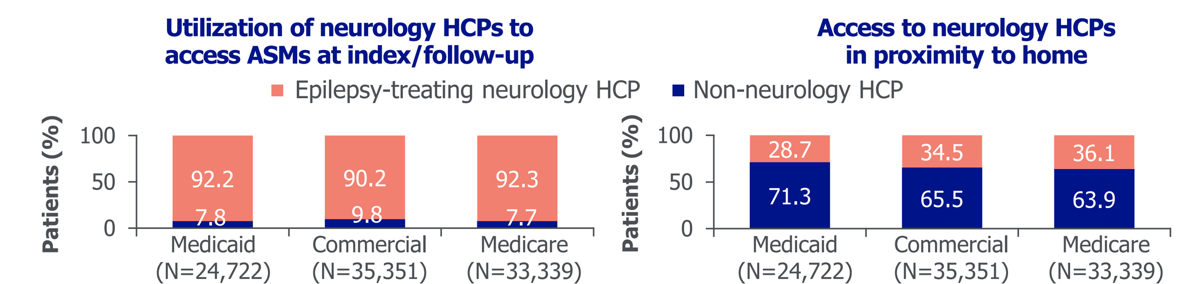
PROPORTION RECEIVING INDEX ASM FROM NEUROLOGY HCP



ASM, antiseizure medication; HCP, healthcare professional.

- For the majority of states, only 21-30% of patients with epilepsy with Medicaid or Medicare and 31-40% with Commercial healthcare insurance received their first ASM from a neurology HCP.

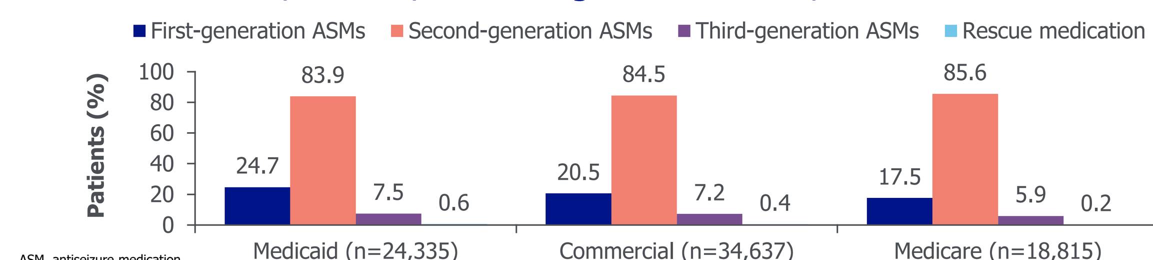
PROVIDER ACCESS BARRIERS



ASM, antiseizure medication; HCP, healthcare professional.

- Although >90% of patients with epilepsy in all insurance groups used a neurology HCP at index/follow-up, only 29-36% lived within proximity.

Utilization of first-, second-, and third-generation ASMs, and rescue medication



ASM, antiseizure medication.

- Of patients with formulary data, >80% were prescribed second-generation ASMs, primarily generic; and <8% used third-generation ASMs.

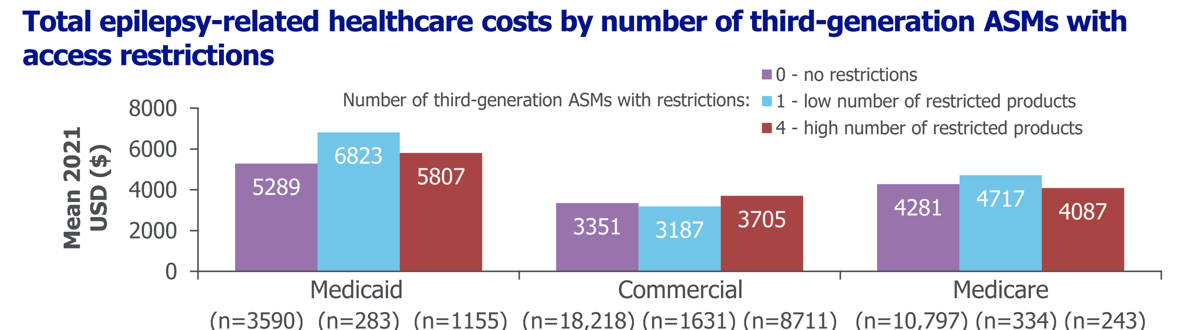
POST-INDEX EPILEPSY-RELATED HCRU AND COSTS

Percentage of patients with epilepsy-related HCRU by number of third-generation ASMs with access restrictions

NO. OF RESTRICTIONS	MEDICAID 0 (no restrictions)	MEDICAID 1 (low no. of restricted products)	MEDICAID 4 (high no. of restricted products)	COMMERCIAL 0 (no restrictions)	COMMERCIAL 1 (low no. of restricted products)	COMMERCIAL 4 (high no. of restricted products)	MEDICARE 0 (no restrictions)	MEDICARE 1 (low no. of restricted products)	MEDICARE 4 (high no. of restricted products)
NO. PATIENTS	3590	283	1155	18,218	1631	8711	10,797	334	243
Inpatient, %	7.2	5.7	6.7	3.6	3.6	4.5	6.1	7.2	5.3
Outpatient, %	38.1	48.8	35.2	29.7	30.6	34.3	32.6	28.7	33.7
Pharmacy, %	93.6	90.5	94.3	96.2	94.7	94.2	95.1	95.5	96.3

ASM, antiseizure medication; HCRU, healthcare resource use; *ICD-9/10-CM, International Classification of* Diseases, *Ninth/Tenth Edition, Classical Modification.*

Total epilepsy-related healthcare costs by number of third-generation ASMs with access restrictions



ASM, antiseizure medication; USD, US dollars.

- There were no notable differences in epilepsy-related HCRU/cost based on number (0-4) of third-generation ASMs with restrictions.

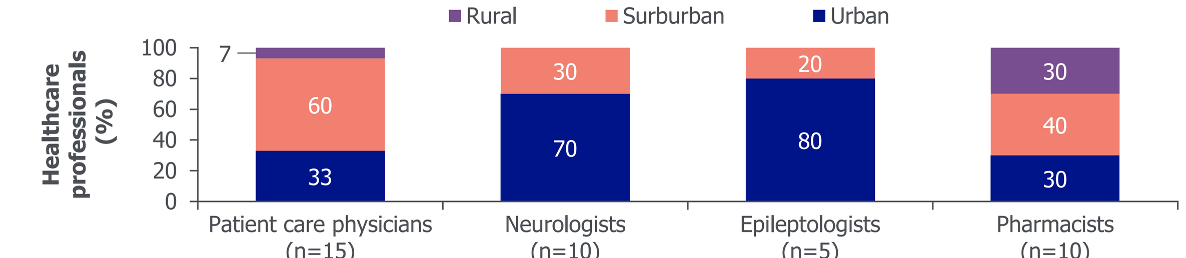
Qualitative study results

INTERVIEW RESPONDENT CHARACTERISTICS

HCP respondents

- Primary care physicians (n=15), neurologists (n=10), and epileptologists (n=5) had 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.
- Pharmacists worked in national retail chains (n=3), hospital pharmacies (n=2), or stand-alone independent pharmacies (n=5), with an average of 12, 12.5, and 16 years in practice, respectively.

HCP practice location



HCP, healthcare professional.

Physician epilepsy population by insurance type (% of patients)[a]

INSURANCE TYPE	PRIMARY CARE PHYSICIAN	NEUROLOGISTS	EPILEPTOLOGISTS
Medicare, %	23	24	28
Medicaid, %	26	30	30
Commercial/private, %	37	36	36
Tricare/other military, %	4	6	2
Plan through ACA Marketplace, %	5	4	3
No insurance/uninsured, %	5	1	1

[a]Epilepsy Discussion Guide (neurologists and primary care physicians) 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.

Non-HCP respondents

- Patient respondents (n=13) had an average age, age at diagnosis, and epilepsy duration of 41, 26, and 17 years, respectively.
  - Insurance types among 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).
- Among 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).

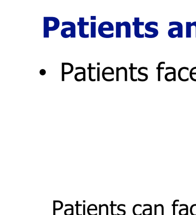
STAKEHOLDERS

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 (first-/second-generation) ASMs.

Neurologists/epileptologists
- Diagnose epilepsy and treat complex cases.
- Most often prescribe the initial ASM.
- Associated with long wait times driven by a shortage of specialists.

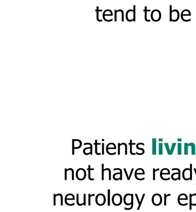
Pharmacists
- Notify HCPs of insurance requirements, but do not navigate the insurance approval process.



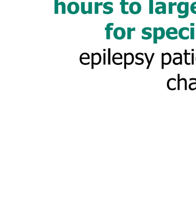
Patient advocates
- Help patients with transport and copay assistance for ASMs (via bridge programs, pharmaceutical companies, or charitable organizations).

Patients and caregivers

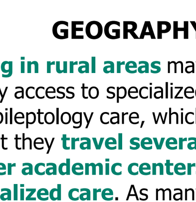
- Patients face many barriers accessing specialist care, driven, in part, by a dearth of neurologists.



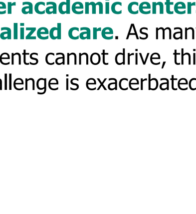
WAITLISTS
Patients can face long **wait times of several months**. These wait times tend to be driven by a **shortage of neurologists**.



GEOGRAPHY
Patients **living in rural areas** may not have ready access to specialized neurology or epileptology care, which can require that they **travel several hours to larger academic centers for specialized care**. As many epilepsy patients cannot drive, this challenge is exacerbated.



MEDICAID
Primary care physicians (PCPs) in this study share that some **local neurology practices accept few to no Medicaid-insured patients**, leaving this patient population to forgo 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

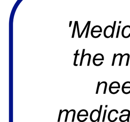
- PCPs and specialists handle insurance rejections differently in terms of investment in the appeals process.
  - PCPs lack training, time, and resources to navigate the insurance appeals process, and often avoid prescribing newer ASMs as a result.
- The appeals process can add up to 6 weeks of treatment delay and is more likely to affect Medicaid patients.
  - This is a frustrating process for specialists to go through.

CHALLENGES FOR MEDICARE AND MEDICAID PATIENTS

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

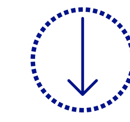
Access to fewer specialists
Not all specialists accept Medicaid. Patients with this insurance have less choice in the specialists they can see.

'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**



'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**

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



Fewer treatment options
High drug costs and lack of formulary coverage mean 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**

PCP, primary care physician.

Conclusions

- Claims data revealed limited neurologist access and predominant use of second-generation ASMs but no notable impact of ASM access restrictions on HCRU and costs. In contrast, access restrictions impacted stakeholder groups.
- Ideally, ASM selection is based on optimizing individual outcomes rather than minimizing restrictions/denials; however, interviews revealed barriers to optimizing treatment and accessing specialty care.
- Future research may identify patient subgroups at risk of negative impact from access restrictions.

References

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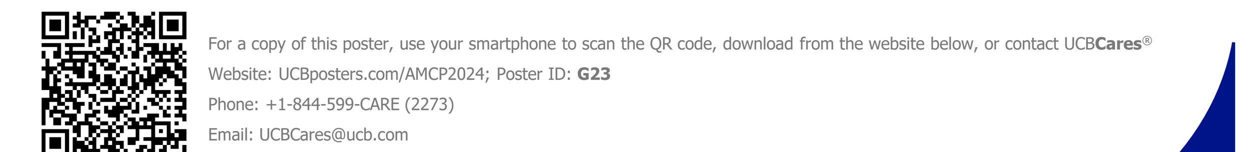

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Email: UCBCares@ucb.com

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