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Barriers to Medication Adherence in People Living With Epilepsy

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Abstract

Background and Objectives

Epilepsy affects approximately 1.2% of the US population, resulting in 3.4 million Americans with active epilepsy. Antiseizure medication (ASM) is considered the mainstay of treatment, effective for two-thirds of people with epilepsy (PWE), while at least one-third experience drug-resistant epilepsy. A significant percentage of PWE who are treated with ASMs report nonadherence to this type of medication, leading to potentially preventable seizures and the potential for being inappropriately classified as having drug-resistant epilepsy. Ongoing seizures are associated with increased morbidity, mortality, and health care costs, among other consequences. Recognizing when PWE struggle with ASM adherence is essential for creating effective interventions and prevention strategies to improve patient outcomes.

Methods

As part of the Epilepsy Learning Healthcare System Registry, we collected data from 2020 through 2023 from 4,917 individuals seen at 8 epilepsy clinics in the United States. In this cross-sectional study, we used logistic regression analysis to examine the relationship between patient-reported seizure control (or provider-reported seizure control for some sites) and endorsed barriers to medication adherence. In addition, we explored potential associations with demographic variables such as sex, race, and ethnicity. The data analysis was conducted using R version 2023.06.1 + 524.

Results

Overall, 18.4% (893/4,848) reported adherence barriers and 37.7% (1,447/3,834) reported seizure control, defined as no seizures for the preceding 12 months or longer. The most prevalent barriers were forgetting to take ASMs (48.2%), experiencing ASM side effects (29.2%), and feeling as if the ASMs were not helping in controlling seizures (21.3%). The PWE who reported adherence barriers had 0.6 lower odds of having seizure control compared with those who did not report barriers (95% CI 0.4–0.7) and 0.6 lower odds of having seizure control after adjusting for race, ethnicity, and sex (95% CI 0.5–0.7).

Discussion

We observed significant barriers to medication adherence and inadequate seizure control among adult PWE across 8 centers in the United States. This study suggests that PWE might benefit from standardized screening for adherence barriers with behavioral strategies to address these barriers offered during clinical encounters to personalize care.

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Epilepsy Learning Healthcare System coinvestigators are listed in the appendix at the end of the article.

Introduction

Epilepsy is a chronic neurologic disorder affecting approximately 50 million people globally and 3.4 million in the United States.[1] People living with epilepsy (PWE) have 3 times higher mortality risk than the general population.[1-3] Approximately 70% of PWE can achieve seizure control if appropriately diagnosed and adequately managed with antiseizure medication (ASM).[1,2,4,5] Although 90% of PWE receive ASMs, only 44% have seizure control, according to US National Health Interview Survey (NHIS) data.[2] This difference in desired vs observed seizure control represents a sizable number of PWE whose seizures could potentially be controlled with appropriate treatment and adherence support.

Adherence among PWE presents a challenge throughout their lives, with nonadherence rates ranging from 29 to 60%, increasing hospital visits and related health care costs.[6] ASM adherence is the degree to which PWE take their prescriptions following the provider's instructions; nonadherence or suboptimal adherence (characterized by a gap in medication possession exceeding 20% of the period between initial dispensing and the measurement period or possession of less than 80% of the prescribed medication)[7] is known to cause breakthrough seizures, exacerbated seizures (i.e., poor seizure control), increased levels of depression and anxiety, reduced quality of life, and elevated mortality rates.[8-10]

While measuring adherence is difficult, studies have found that adherence barriers and rates are intrinsically linked, and thus, understanding these in clinical practice allows us to address this important construct proactively.[11] Barriers to adherence are stable and do not change without intervention, but they exhibit variability across developmental stages.[9] This study examines barriers to ASM adherence reported by PWE through the implementation of the Barriers to Adherence Tool (BAT; eTable 1 and eAppendix 1)[11] in 8 epilepsy centers participating in the Epilepsy Learning Health System (ELHS) across the United States. We hypothesize a negative correlation between barriers to ASM adherence and seizure control.

Methods

Study Design

As part of a quality improvement (QI) initiative, 8 tertiary epilepsy sites implemented ELHS case report forms (CRFs) in their clinical practice and collected data from March 20, 2020, to October 31, 2023. These data were transferred to the ELHS National Registry and aggregated for analysis. For this study, we sampled cross-sectional data.

Interventions

Data Collection

The ELHS National Registry is populated through different data sources collected by providers and PWE (or caregivers, parents/guardians, or legally authorized representatives) through the ELHS provider-reported and patient-reported outcome (PRO) CRFs, respectively.[12] As part of clinical care and quality improvement activities, we collect information about patient demographics, epilepsy history, seizure frequency, ASM use, adherence and side effects, quality of life, mental health, and women's health. Providers also collect details about seizures, such as seizure type (i.e., International League Against Epilepsy [ILAE] classification), frequency, and date of last seizure. In this study, we analyzed seizure and barriers to adherence data.

Data collection methods have been previously described in more detail,[12] and they vary from site to site. Sites have implemented data collection systems that fit their workflow with local resources. In Figure 1, we illustrate how one ELHS site collects PROs. Other sites collecting PROs use paper forms, which are later entered into their local databases and then shared with the ELHS Data Coordinating Center (DCC) for processing. The DCC enters all sites' data into the ELHS National Registry. As for provider-reported outcomes CRFs, some sites have been able to implement these in their electronic health records (EHRs) and providers complete these for patients' first visits (the full set) and follow-up visits (only seizure form and epilepsy clinic visit form).

Study Sample and Setting

The ELHS National Registry includes people of all ages with epilepsy or seizures (and being evaluated for epilepsy). For this study, we included data of adults aged 18 years or older from all participating sites, collecting seizure data and the BAT. There were 8,832 unique individuals aged 18 years and older and 4,917 individuals with PROs in the ELHS National Registry data collected from 2020 to 2023. After excluding individuals who did not complete the BAT (N = 69), 4,848 individuals remained for analysis.

Measures

Definitions

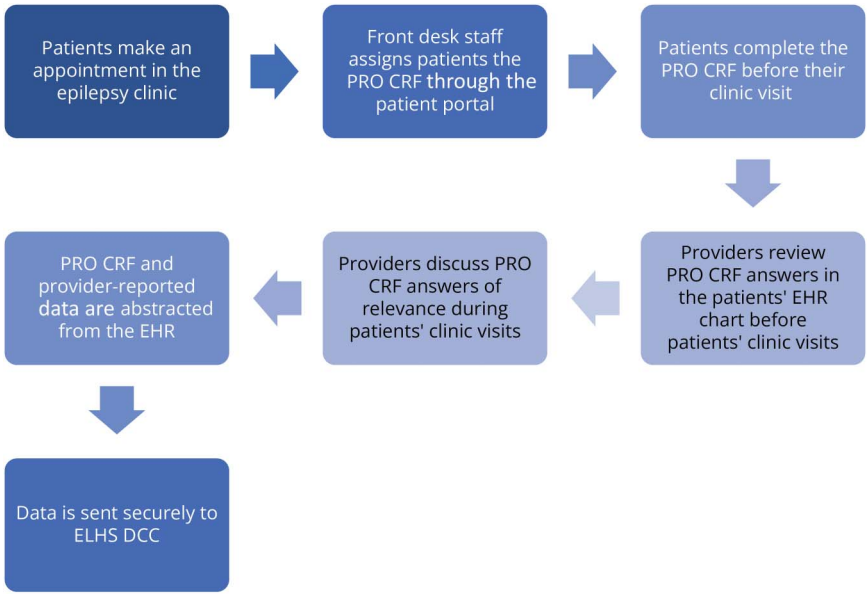
The BAT includes 17 items derived from validated tools from other chronic disease groups.[8,9,11,13-15] There is an additional option of "other" and an option if the patient has not experienced any barrier to adherence. The complete checklist is included in the supplement, item A.

The ILAE defined "seizure freedom" as a metric where no seizure episode or aura occurs "for at least 12 months or 3 times the preintervention interseizure interval, or whichever is the longest".[16] Because this is a cross-sectional analysis, we use "seizure control" instead and define it as the absence of seizure activity for at least 12 months from their visit date.[17]

Analysis

Data analysis was performed using the R programming language version 2023.06.1 + 524. Categorical variables were presented as frequencies and percentages while continuous variables were displayed as means and standard deviations. The relationships between patient-reported seizure control

Figure 1 Example of Patient-Reported Outcome Data Collection in an ELHS Site



This workflow demonstrates how one ELHS site collects data in their outpatient Epilepsy Clinic. Leveraging institutional resources, this site was able to program patient-reported outcome (PRO) case report forms (CRFs) into the patient portal and the provider-reported outcome CRFs into their electronic health records (EHRs). DCC = Data Coordinating Center; ELHS = Epilepsy Learning Healthcare System.

and barrier to adherence were analyzed using standardized mean difference (SMD) and logistic regression [odds ratios (ORs)]. For SMD, effect size values of 0.2 are considered small, 0.5 medium, and 0.8 large, respectively.

Standard Protocol Approvals, Registrations, and Patient Consents

This report follows the guidelines for the Revised Standards for QI Reporting Excellence (SQUIRE 2.0; eTable 2).[18] This study received approval from a central institutional review board, the Western Institutional Review Board, and the Mass General Brigham Healthcare Institutional Review Board. The requirement for informed consent was waived because the data analyzed for this study were collected as part of routine clinical care, deidentified, abstracted retrospectively, and aggregated for analysis.

Data Access

We take full responsibility for the data, the analyses and interpretation, and the conduct of the research. We have full access to all the data collected in the ELHS National Registry.

Data Availability

Anonymized data not published within this article will be made available by request from any qualified investigator.

Results

Sample Demographics and Barriers to Medication Adherence

A demographic summary of the sample stratified by individuals reporting a barrier to adherence and seizure control is given in Table 1. Of the 4,917 individuals who completed PROs, the mean age was 42.8 years (SD 17.5), 53.7% were female, 44.6% were male, and less than 1% were missing sex. A total of 2,742 individuals (55.8%) reported gender identity, with most individuals identifying as women (31.6%) or men (23.4%), 30 individuals (0.6%) identifying as part of the sexual and gender minority (SGM) community, and 44.2% missing gender identity. Of the 4,917 individuals in the sample, 77.0% were White, 9.4% were Black, 2.2% were Asian, 4.4% reported as "other," 0.8% chose not to disclose, and 6.1% were missing race. By ethnicity, 88.4% were non-Hispanic, 7.2% were Hispanic or Latino, 2.9% chose not to disclose, and 1.4% were missing ethnicity.

Of the 4,917 individuals who submitted a PRO form, a total of 4,848 completed the BAT checklist and 3,834 responded to the date of the last seizure question. Overall, 18.4% (893/4,848) of individuals reported a barrier to adherence and 37.7% (1,447/3,834) reported good seizure control (i.e., had no seizures within the last year of the current visit). The mean age of individuals reporting an adherence barrier was 40.1 years (SD 16.0) compared with 43.5 years (SD 17.7) who did not report barriers (SMD 0.2). By sex, 18.0% of men (398/2,211) and 18.8% of women (489/2,608) reported barriers, and by gender identity, 18.4% (209/1,136) of men, 19.7% (302/1,535) of women, and 26.7% (8/30) of the SGM community reported barriers to adherence. By race, 18.0% (676/3,754) of White, 24.1% (112/464) of Black, 18.5% (20/108) of Asian, and 22.3% (47/211) of other individuals reported barriers. By ethnicity, 23.5% (80/341) of individuals who identified as Hispanic or Latino reported barriers to adherence compared with 18.3% (787/4,297) of individuals who did not identify as Hispanic or Latino.

Table 1 Demographics of Patient-Reported Barriers to Medication Adherence Toolkit (BAT) and Seizure Control

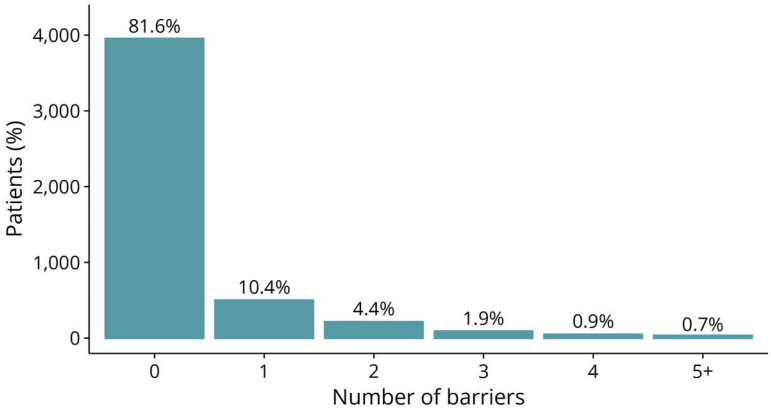
		BAT[c]					Seizure control[a]				
	Overall	N complete	Yes	No	Percentage yes (%)	SMD	N complete	Yes	No	Percentage yes (%)	SMD
N	4,917	4,848	893	3,955	18.4%		3,834	1,447	2,387	37.7%	
Age, mean (SD)	42.8 (17.5)	4,848	40.1 (16.0)	43.5 (17.7)	NA	0.20	3,834	46.0 (17.6)	42.7 (16.7)	NA	0.19
Sex[b] (%)						0.03					0.03
Female	2,642 (53.7)	2,608	489	2,119	18.8%		2,057	790	1,267	38.4%	
Male	2,243 (45.6)	2,211	398	1,813	18.0%		1,750	646	1,104	36.9%	
Missing	32 (0.7)	29	6	23	20.7%		27	11	16	40.7%	
Gender identity (%)						0.10	0				0.12
Man	1,149 (23.4)	1,136	209	927	18.4%		906	322	584	35.5%	
Woman	1,553 (31.6)	1,535	302	1,233	19.7%		1,228	433	795	35.3%	
SGM[c]	30 (0.6)	30	8	22	26.7%		18	5	13	27.8%	
Declined to answer	10 (0.2)	10	3	7	30.0%		9	3	6	33.3%	
Missing	2,175 (44.2)	2,137	371	1,766	17.4%		1,669	680	989	40.7%	
Ethnicity (%)						0.13	0				0.11
Not Hispanic/Latino	4,347 (88.4)	4,297	787	3,510	18.3%		3,475	1,340	2,135	38.6%	
Hispanic/Latino	355 (7.2)	341	80	261	23.5%		184	53	131	28.8%	
Declined to answer	145 (2.9)	142	19	123	13.4%		117	34	83	29.1%	
Missing	70 (1.4)	68	7	61	10.3%		58	20	38	34.5%	
Race (%)						0.17	0				0.17
White	3,787 (77.0)	3,754	676	3,078	18.0%		3,069	1,203	1,866	39.2%	
Black/African American	464 (9.4)	464	112	352	24.1%		381	119	262	31.2%	
Asian	110 (2.2)	108	20	88	18.5%		90	41	49	45.6%	
Other	214 (4.4)	211	47	164	22.3%		164	51	113	31.1%	
Declined to answer	40 (0.8)	38	6	32	15.8%		34	6	28	17.6%	
Missing	302 (6.1)	273	32	241	11.7%		96	27	69	28.1%	

SMD, standardized mean difference compares means or proportions between 2 groups (yes/no). Effect size values of 0.2 are considered small, 0.5 medium, and 0.8 large, respectively. BAT refers to the Barriers to Adherence Tool, where "yes" indicates patients reported a barrier and "no" indicates they did not report a barrier. NA means not applicable.
[a] Seizure control is defined as a patient-reported frequency of no seizures in more than 1 y or 12 mo.
[b] Sex refers to sex assigned at birth.
[c] Sexual and gender minority (SGM) population includes gender nonbinary, genderqueer, gender nonconforming, transgender, and others.

Numbers and Types of Barriers to Medication Adherence

Of individuals who reported barriers, 506 (10.4%) reported 1 barrier to adherence, followed by 215 (4.4%) who reported 2, 92 (1.9%) who reported 3, and 80 (0.9%) who reported 4 or more barriers to adherence (Figure 2). The most prevalent barrier to adherence was forgetfulness (i.e., having trouble remembering; 48.2%), followed by experiencing side effects (29.2%) and ASMs not helping in controlling seizures

Figure 2 Numbers of Barriers to Medication Adherence Reported per Patient



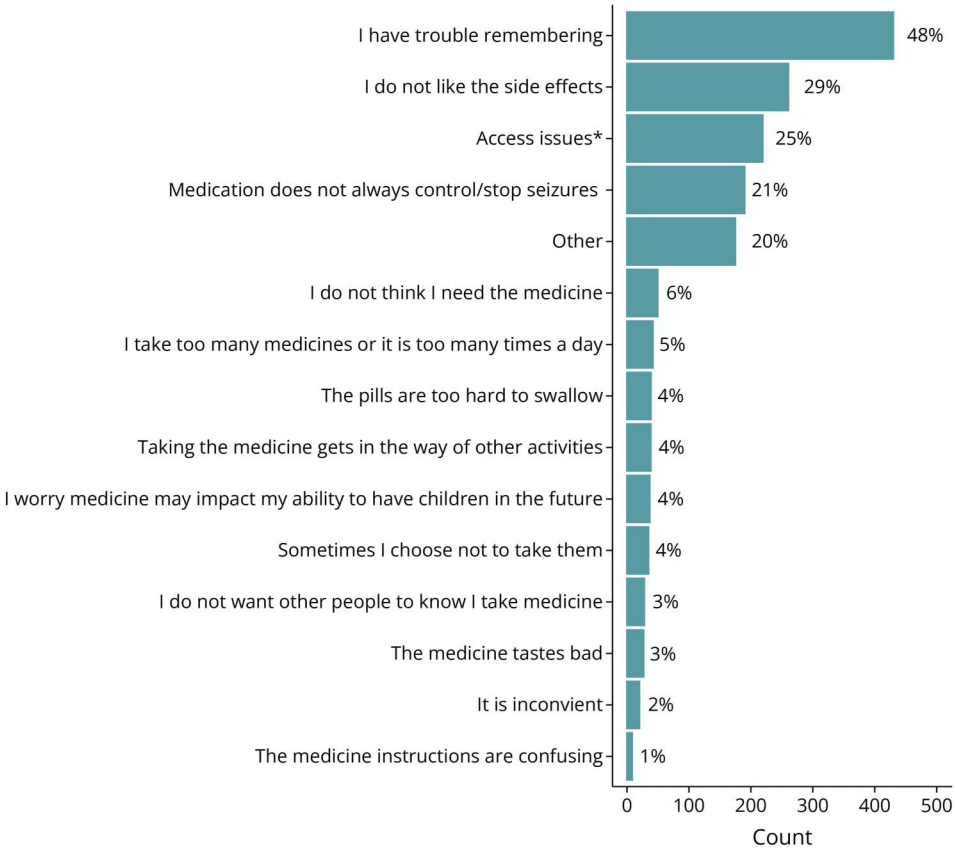
The number of barriers to medication adherence reported by the patient out of a checklist of 17 potential barriers, using patient-reported outcomes from PWE last visit.

(21.3%). Figure 3 shows the frequencies of reported barriers to adherence.

Barriers to Medication Adherence and Patient-Reported Seizure Control

Of the PWE who reported any barrier to adherence, 26.3% (n = 130) had their last seizure more than 1 year ago while 73.6% (n = 364) had 1 or more seizures in the previous year. Moreover, of the PWE who did not endorse any barriers, 39.4% (n = 1,317) had seizure control while 60.5% (n = 2,023) met the criteria for uncontrolled seizures. The PWE who endorsed an adherence barrier had 0.6 (95% CI 0.4–0.7) odds of having seizure control compared with those who did not report barriers (Table 2). After adjusting for

Figure 3 Count of PWE Reporting Each Barrier to Medication Adherence With the BAT



Included in the patient-reported outcomes is the BAT reported by PWE out of 17 potential barriers. PWE can report multiple barriers, so counts will not add to the total number of individuals. Percentage is calculated as the number of PWE reporting the barrier out of the total number of PWE. *Access issues include "I run out of medicine," insurance problems, "difficulty getting to pharmacy to pick up medicine," and "I cannot afford the medicine." BAT = Barriers to Medication Adherence Toolkit; PWE = people with epilepsy.

Table 2 Logistic Regression of Patient-Reported Seizure Control

Independent variable	Estimate	Standard error	Probability	Odds ratio (95% CI)
Barrier to medication adherence (yes/no)				
Crude	−0.600	0.108	<0.001	0.6 (0.4–0.7)
Adjusted for race + ethnicity + sex	−0.585	0.109	<0.001	0.6 (0.5–0.7)
Number of barriers to medication adherence				
Crude	−0.408	0.068	<0.001	0.7 (0.6–0.8)
Adjusted for race + ethnicity + sex	−0.395	0.069	<0.001	0.7 (0.6–0.8)

Abbreviations: BAT = Barriers to Medication Adherence Toolkit; PWE = people with epilepsy.
Here, n = 3,834 with complete BAT and seizure control. Of the PWE who reported any barrier to adherence, 26.3% (n = 130/494) had their last seizure more than 1 year ago while 73.6% (n = 364/494) had 1 or more seizures in the previous year. Moreover, of the PWE who did not endorse any barriers, 39.4% (n = 1,317/3,340) had their last seizure more than 1 year ago while 60.5% (n = 2,023/3,340) had 1 or more seizures in the previous year.

race, ethnicity, and sex, the odds ratio for seizure control was 0.6 (95% CI 0.5–0.7) (Table 2). In addition, as the number of barriers to adherence increased, the odds of achieving seizure control significantly decreased. When controlling for race, ethnicity, and sex, each additional barrier to adherence was associated with approximately 30% decrease in the odds of seizure control (OR 0.7, 95% CI 0.6–0.8; Table 2).

Discussion

We examined seizure control and barriers to adherence among PWE aged 18 years and older who were seen for routine clinical care at ELHS sites. The results provide a cross-sectional analysis of seizure metrics from the ELHS National Registry. We observed that barriers to adherence are negatively associated with seizure control. The results revealed that approximately 37.7% of PWE at participating epilepsy centers had controlled seizures, comparable with the existing literature in which less than half of PWE reported achieving seizure control in the past year.[2,19] In our study, 18.4% of PWE reported barriers when taking their ASMs.

Assessing self-reported BAT is a pragmatic approach to monitoring ASM adherence outside controlled trials where measuring drug levels or monitoring pill bottles may be more appropriate. While known barriers to medication adherence vary from disliking taste, forgetfulness, adverse effects, and medication management–related issues,[9,19-23] forgetfulness has been recognized as the most common barrier, with 48.7% of PWE endorsing forgetting to take their ASM.[15,24,25] In our study, the most frequently reported barriers by PWE were forgetfulness (48%), side effects (29%), and ineffective ASMs (21%; Figure 3).

Medication nonadherence is a significant global health concern and remains prevalent among PWE, where nonadherence rates can vary from 30% to 50%.[9,19-21] Nonadherence to ASMs is related to an increased probability of emergent hospitalization and higher health costs and[26] an increased likelihood of breakthrough seizures, uncontrolled seizures (30% of these are connected to ASM nonadherence),[27] poor quality of life, and impaired productivity.[24,28-30] In an international study, people who experienced adverse effects from ASMs were almost 3 times more likely to be nonadherent compared with those who did not experience any side effects.[27] On the contrary, in a cross-sectional observational study, adherence to ASMs was positively associated with better seizure control.[31] Among those who were adherent to ASMs, a significant majority (82.4%) achieved seizure control.[31]

A critical distinction must be made between PWE whose seizures do not respond to treatment (drug-resistant epilepsy with an incidence of 19.6% and a prevalence of 32.4%)[32] and those whose seizures are uncontrolled because of suboptimal adherence (i.e., they experience a barrier to taking an ASM that would be effective as prescribed) because both require different interventions. Behavioral interventions (i.e., intensive reminders and "implementation intention" interventions) have proven more successful in improving PWE ASM adherence than education or counseling.[33] Multicomponent behavioral interventions developed in pediatric epilepsy, including problem solving, education, and digital health solutions, have also been proven effective.[34,35] Other seemingly straightforward interventions to address adherence difficulties (e.g., special packaging of medications, pill boxes, physical reminders, mail-order pharmacy services, and medical team addressing PWE's perceived adherence obstacles)[36,37] can, in reality, be timely, costly, and more complex to execute and especially challenging and less successful for those with comorbidities (i.e., polypharmacy and mental health comorbidities) and drug-resistant epilepsy. PWE with drug-resistant epilepsy should be evaluated for surgical (e.g., resection/ablation surgical therapy, devices, neuromodulation with vagus nerve stimulation, responsive neurostimulation, and thalamic deep brain stimulation)[38] and dietary (e.g., ketogenic diet, modified Atkins diet, low glycemic index treatment, and medium-chain triglyceride diet) treatment options for seizure

reduction and control, or participation in clinical trials of new therapies should be discussed.[24]

In our study, 1% of barriers were attributed to confusing medication instructions or inconvenient processes for taking them (Figure 3). In a different study, people who did not receive sufficient health information regarding their epilepsy diagnosis, treatment duration, and ASM side effects were 2.2 times more likely to be nonadherent than those who received adequate information.[39] Studies have also demonstrated that PWE are more likely to discontinue their ASMs once their seizures are under control or when they experience ASM side effects unless they receive proper education and information about their condition.[31,40]

We also observed that more barriers were reported by the Black/African American, Hispanic, and SGM groups. The prevalence and disparities in ASM adherence and resulting variability in seizure control stem from clinical, environmental, and social factors. These include socioeconomic and employment status, education level, marital status, and social determinants of health (i.e., behavior and psychosocial factors). Underlying comorbidities further complicate care, adherence, and outcomes.[4,41] Complex treatment regimens and disparities in access to specialized clinical services also contribute to health disparities and outcomes.[4,5,20,26] Previous extensive research studies have highlighted prevalent suboptimal self-management skills among PWE (i.e., barriers to medication adherence), notably among Black communities. This disparity, compounded by reduced access to specialized epilepsy care (70% less than their White counterparts), results in triple the number of emergency department visits for seizure emergencies among Black individuals and an increased frequency of hospitalizations due to seizure-related incidents.[42]

In previous studies, Black PWE endorsed system-level and community-level barriers (e.g., receiving inconsistent education, inadequate understanding of complex information, running out of ASMs, access to pharmacies, and putting off refilling medicines) at higher rates than White PWE.[42-44] The under-representation of racial minorities in clinical trials that lead to the approval of new ASMs is a historic and ongoing concern. PWE of different races and ethnicities may have different comorbidity and side effect profiles and require further investigation in new and more thorough clinical trials.[45] Furthermore, as newer treatment options for epilepsy become available, this often translates to higher treatment costs and access challenges, including limited availability and lack of insurance coverage (insurance companies capping refills on certain medications or the number of pills PWE are given at a time, requiring PWE to keep close attention as to when they will necessitate refilling their prescriptions), which could influence ASM adherence.[20,46]

The challenge of medication adherence manifests diversely among individuals, influenced by multifaceted factors. Our study aimed to comprehensively assess the adherence landscape within our patient cohort, albeit limited to those individuals attending tertiary epilepsy centers with specialized care, nevertheless highlighting the lack of access to care for minoritized populations. Through ELHS, a collaborative initiative uniting medical experts, health care professionals, researchers, community stakeholders, and patient advocates, we have catalyzed transformative improvements in epilepsy care delivery and patient outcomes.

Our findings highlight the importance of routinely screening and assessing PWE with BAT. This will allow for managing barriers to adherence, ASM side effects, and community referrals to help PWE overcome barriers. In fact, the Joint Commission has introduced new requirements for assessing patients' health-related social needs and providing information about community resources and support services, among multiple requirements to reduce health care disparities.[47] Indeed, to devise a successful and personalized treatment plan, an appropriate ASM must be selected based on accurate epilepsy classification and proven successful interventions to address barriers to adherence must be deployed when warranted. Successful interventions will be those that take into consideration factors such as age, race, ethnicity, biological sex, gender identity, medical comorbidities, and other social determinants and will include a comprehensive approach while using bidirectional communication among health care providers and external institutions that can support PWE with additional resources (e.g., community agencies and nonprofit organizations, community health care workers, and support groups). Different interventions must be planned, tested, and analyzed on a system level to address these barriers. Successful interventions must be implemented in standard practice to improve seizure control, health outcomes, and overall quality of life for PWE.

While most ELHS participating sites have implemented the provider-reported outcome CRFs into their EHR and clinical workflow, some sites are not currently collecting PROs or the BAT and thus were not included in this study. Sites that have been able to implement PROs in their clinical practice have done so in several different ways (Figure 1 exemplifies one). Challenges in this implementation are varied; most have come to light and addressed, thanks to previous QI efforts. These range from lack of staff and institutional-level (such as lack of IT or research staff support) to patient-level barriers (e.g., patients unable to access their patient portal to complete their PROs or a language barrier). In one site, there was an institutional initiative to implement PROs in the patient portal, which allowed ELHS CRFs to be programed so that patients would be assigned their PROs before their clinic visit. The site encountered through Plan-Do-Study-Act cycles that not all patients were being assigned PROs and, on further investigation, was able to update the codes Front Desk staff were using so all patients, regardless of if it was an initial encounter, a follow-up, an in-person, or virtual visit, could receive their PROs. This site also leveraged its institution's effort to translate all PROs into multiple languages. A different site leveraged its local REDCap database and enabled the survey functionality to collect PROs.

We could not determine outcome and exposure temporality because we are examining snapshots of registry data. Another limitation is recall bias during patient information reporting because many questions are structured to capture clinical history from previous weeks, months, or years. In addition, our sample population may be biased because it includes only individuals seen at Level 4 epilepsy centers who may have more complex care needs and may be more likely to have drug-resistant epilepsy. We may overestimate the number of people with barriers because people with barriers may be more likely to respond to the questionnaire than those who do not have barriers. We have minimized this bias through quality improvement efforts to increase the patient-reported outcome response rate. Conversely, our study may underestimate barriers to adherence because we used PROs to assess both seizures and barriers to adherence. The 3,915 adult PWE who did not complete the PROs from the included sites (1 of 9 sites was not collecting PROs) may differ in important ways influencing ASM adherence.

We envision continuing to leverage and engage more community-based health care facilities. This will enable collaborative endeavors and the integration of support mechanisms facilitated by community health workers to mitigate disparities stemming from structural inequities, including barriers to care access, disparities in specialized care provision, and educational deficiencies, often exacerbated by systemic racism.

This will be critical in connecting patients with essential resources, facilitating access to health care facilities, assisting with medication procurement, arranging transportation, and providing comprehensive guidance on medication management protocols. These interventions will be crucial to sustaining long-term medication adherence.

We found that a significant number of adults with epilepsy identified barriers to adherence and uncontrolled seizures. Although our data represent a snapshot from a longitudinal registry, they highlight gaps in clinical care that can be targeted for improvement. Some examples include aiming to increase the patient response rate to PRO CRFs, documenting and tracking barriers to adherence and ASM side effects, addressing barriers to adherence through personalized support, and connecting PWE to community resources. A standardized BAT was tested and implemented in ELHS centers using QI methodology in routine clinical practice. Additional quality improvement studies and implementation research projects are urgently needed to address ASM adherence challenges in epilepsy and multiple other chronic conditions.[48-50]

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TAKE-HOME POINTS

- Standardized screening for barriers to medication adherence can help provide personalized care to address them.
- Barriers to medication adherence are negatively associated with seizure control among people living with epilepsy.
- The most frequently reported barriers by people living with epilepsy were forgetfulness, side effects, and ineffective medication.
- Reporting the most barriers to medication adherence were Black/African Americans, Hispanics, and sexual and gender minorities.

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Continued

Appendix 1 *(continued)*

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Appendix 1 *(continued)*

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