

IMPROVING CONTINUITY OF CARE IN EPILEPSY

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I. Introduction

Epilepsy is the 4th most common neurologic disorder in the United States, after migraine, stroke, and Alzheimer's disease.¹ Between 2 million and 3 million people in the United States are estimated to have epilepsy, with 150,000 Americans diagnosed every year.^{1,2} In fact, as many as 1 in 26 people will develop epilepsy at some point in their lives.^{1,3}

For many of these patients, seizures may be effectively reduced or eliminated through the use of medications, surgery, devices, dietary adjustments, or other therapies.¹ However, it is estimated that 30% of patients with epilepsy experience uncontrolled seizures despite available treatments.^{4,5} Even for patients who consider their seizures well controlled, medical and psychiatric comorbidities and psychosocial problems—including fear, uncertainty, and depression—may persist.⁶ This reflects a pressing need to improve the overall quality of care for patients with epilepsy.

In 2011, the American Academy of Neurology (AAN) developed 8 quality measures to help improve the quality of care for patients with epilepsy.⁷ Three of these quality measures were adopted in 2012 by the Centers for Medicare and Medicaid Services' Physician Quality Reporting System^{8,9}:

- Documentation of seizure type and current seizure frequency
- Documentation of etiology of epilepsy or epilepsy syndrome
- Counseling for women of childbearing potential with epilepsy

Similarly, the Department of Health and Human Services includes an epilepsy-specific measure

(ie, increase the proportion of people with epilepsy and uncontrolled seizures who receive appropriate medical care) as part of its Healthy People 2020's 10-year agenda to improve the nation's health.¹⁰ The Institute of Medicine (IOM) also emphasized the need for improved epilepsy care in their 2012 report *Epilepsy Across the Spectrum*.¹

Despite this focus on quality care in epilepsy, gaps in care still remain. Current quality measures do not focus on outcomes, but rather address process measures (including diagnosis and safety). Further study is required to demonstrate the link between specific process measures (such as documentation of seizure type or etiology) and related outcomes.⁷

Moreover, performance on these measures widely varies. One study published in 2012 found that 88% of patients are confident they know the name of the seizures they experience. The same study also discovered that only 48% of eligible patients are referred to an epilepsy surgery or non-pharmacologic treatment specialist.¹¹ Thus, gaps remain in the quality and continuity of care for patients with epilepsy.

II. Continuity of care is critical in epilepsy management

As they navigate the healthcare system, patients with epilepsy encounter a variety of healthcare professionals. These patients may be diagnosed and treated by primary care physicians (PCPs), neurologists, epileptologists, and neurosurgeons while trying to achieve seizure control. In addition, patients with epilepsy may be treated for comorbid conditions by specialists, such as psychiatrists, to address depression and anxiety. They may also interact with an array of nurse practitioners, hospitalists, and case managers.¹

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Despite all of these stakeholders involved in a patient's care, a large gap remains in the coordination and continuity of this care. For instance, one study showed that the median time for a patient with seizures unresponsive to antiepileptic drug (AED) therapy to be referred to an epilepsy center for evaluation far exceeded the recommended 1-year threshold for consideration for referral.¹² According to the IOM report, referrals to epileptologists and epilepsy centers for surgical consultations may take 15 years or more.¹ Moreover, there is a shortage of epilepsy centers as well as other limitations in access due to location of services with limited transportation options. Patients may also lack sufficient coverage of certain services in health insurance plans and may not understand the fundamentals of care they are entitled to, due to the complex nature of these plans.^{1,12,13}

Better collaboration throughout the care continuum for patients with epilepsy can improve the quality and continuity of care.

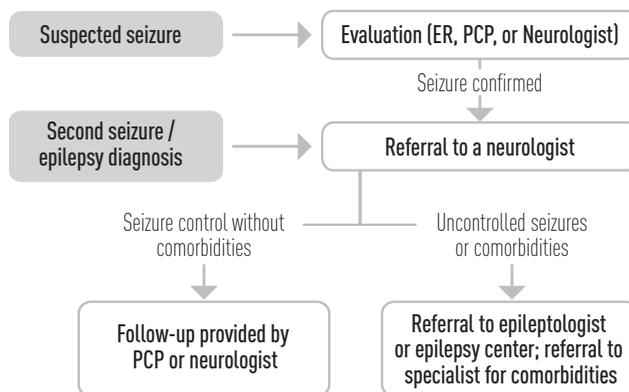
III. Primary care – the first step in managing epilepsy

For patients with epilepsy, the journey through the healthcare system often begins with a PCP. Only 17% of patients with new-onset epilepsy are evaluated by a neurologist. PCPs also provide the majority of the day-to-day care and treatment for approximately 40 percent of epilepsy patients.¹ Some studies report that the number of patients with neurological conditions who are cared for in primary care settings is increasing.^{1,14} Consequently, PCPs are an important touch point in the care continuum for patients with epilepsy.

Epileptologists, neurologists, professionals in epilepsy care, and patients have conflicting views about the role the PCP should play, as it is not well defined.¹⁵ According to the National Association of Epilepsy Centers (NAEC), PCPs will often be the first-in-line to evaluate a patient following a suspected seizure. If a patient does not attain seizure control within 3 months, the NAEC recommends a PCP refer the patient to a general neurologist.¹⁶ PCPs may also be expected to coordinate care for patients as they navigate through the healthcare system. Likewise, as shown in Figure 1, PCPs might be responsible for the follow-up care provided to patients following seizure control.¹

As PCPs play such an integral role in epilepsy care, it is essential to clarify the role of the PCP within the epilepsy care continuum.

Figure 1: Common referral paradigm for patients with epilepsy¹



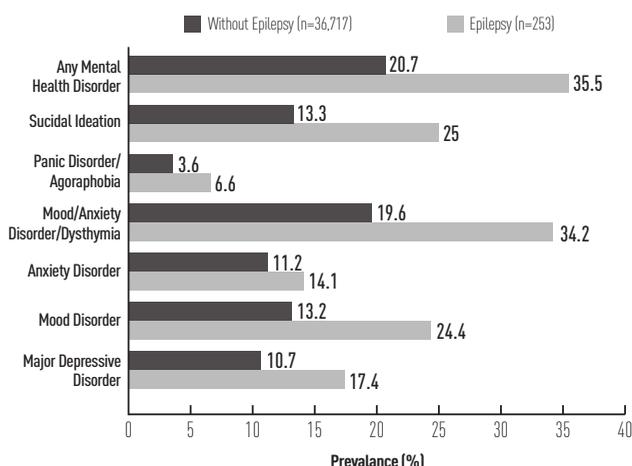
For PCPs who do find themselves as the first-in-line physician for patients with new-onset seizures, diagnosis may be made more difficult by the complexities of epilepsy. Clinicians rarely have the opportunity to see a seizure take place, and instead must rely on the patient or caregiver's description of events. Additionally, the numerous types of seizures, including non-epileptic seizures, and the more than 25 epilepsy syndromes may confound diagnosis.^{1,17} Indeed, it has been found that approximately 25% of patients who have received a diagnosis of epileptic seizures and are uncontrolled despite therapy have actually been misdiagnosed.¹⁷

Even with a proper diagnosis, PCPs may not be aware of the many different modalities available to treat epilepsy, such as AEDs, surgery, and diet.^{1,18} While AEDs are the most common treatment for patients with epilepsy, there are now more than 20 different AEDs available. There are also many intricacies involved in decision-making about AED selection (dosing, potential adverse effects, and drug interactions), which can make the management of individuals with even well-controlled seizures challenging.⁵

In order to help with this complexity, there is a need for clear guidelines, outlining specific medications to use under certain conditions.¹⁵ Helpful guidance may include how to discontinue a medication, lower the dose, and choose the optimal replacement for a medication that has induced an adverse event. Patients with uncontrolled seizures may also benefit from non-pharmacological treatments, such as surgery, surgical devices (eg, vagus nerve stimulation), and dietary adjustments.¹⁸ However, PCPs may not have in-depth knowledge of these options.¹

In addition to the complications of diagnosis and treatment, comorbidities are also common in patients with epilepsy. For example, patients with epilepsy have increased risk of migraines, bone fracture (from injury), sexual dysfunction, and reproductive issues. In addition, patients with epilepsy often suffer from psychiatric comorbidities, such as depression and anxiety. There is also risk of suicidal ideation and cognitive impairments (Figure 2). For example, approximately 50% of patients with uncontrolled partial-onset seizures suffer from some form of depression, and often it is underdiagnosed or untreated.¹⁸ Even among community-based epilepsy patients, mild-to-moderate or severe depression occurs in a third of individuals.¹⁹ Quality of care for patients with epilepsy may improve with better screening for comorbidities, proper patient inquiries, and reinforcement of quality measures through the electronic medical record (EMR) system.²⁰

Figure 2: Lifetime prevalence of psychiatric comorbidities¹⁸



The current difficulties in diagnosis and treatment may explain why many PCPs report that they are not confident in treating epilepsy. According to one study published in 2000, most PCPs claim that they are uncomfortable with the evaluation and treatment of epilepsy. Thus, a majority of PCPs (84.4%) are very likely to refer a patient to a neurologist for treatment.²¹

The creation and dissemination of epilepsy education materials may be one way to better support PCPs.

PCPs, especially those who do not feel comfortable treating patients with epilepsy, may benefit from additional educational resources on epilepsy (including continuing medical education and electronic tools, such as webinars).^{22,23} According to the 2012 IOM report, healthcare professionals may not have access to up-to-date information about many aspects of epilepsy. PCPs in particular may require more information on seizure recognition, diagnosis, treatment options, and prevention.¹

Although the AAN develops and provides such information to family care physicians, the curricula may not be widely used or leveraged in education programs. In addition, time constraints may pose another barrier to physician education. To overcome these obstacles and make epilepsy a greater priority, educational programs and courses should be tailored to better address the audience's needs, preferences, and time restrictions.¹ Research should also be conducted to better identify ways to update, disseminate, and support physician education on epilepsy.

IV. The need for appropriate referral

PCPs are only the first link in the care continuum for patients with epilepsy. A patient should be referred to an epileptologist or epilepsy center if¹:

- The patient's diagnosis is in question
- The patient does not achieve seizure control after failing 2-3 seizure medications or after 1 year of treatment by a neurologist

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However, referral patterns vary among epilepsy healthcare professionals. Neurologists are less likely than PCPs to refer patients to a higher level of care, representing a large gap in the quality of care for patients with epilepsy.¹

Higher levels of epilepsy care can both reassess a diagnosis (including confirming the diagnosis of epilepsy or recognizing non-epileptic diagnoses such as psychogenic non-epileptic events) and determine whether a different treatment modality may be more effective in managing a patient's epilepsy.^{24,25} For instance, evaluation at an epilepsy center may be able to determine if a patient's uncontrolled seizures are the result of an improper selection of medication or inadequate dosing.²⁴ Despite this valuable offering, the average time to referral often takes more than 15 years, far exceeding recommended guidelines.^{1,12}

One reason that may cause delays in referral is the ambiguity surrounding the definition of what constitutes uncontrolled seizures (also referred to as "refractory," "drug-resistant," or "intractable").^{26,27} In one of the 8 AAN quality measures—*Surgical Therapy Referral Consideration for Intractable Epilepsy*—the AAN offers its own definition²⁸:

- Intractable epilepsy: the failure of appropriate trials of first-line AEDs

Notably, the criteria for failure of drug treatment have not been definitively established.²⁸ Recognizing the need for a more standardized definition, the International League Against Epilepsy has proposed a consensus definition²⁹:

- Drug-resistant epilepsy: failure of adequate trials of two tolerated and appropriately chosen and used AED schedules (whether as monotherapies or in combination) to achieve sustained seizure freedom

Establishing and disseminating a standardized definition of "uncontrolled" seizures can support appropriate referral patterns.

Lack of patient referral to more specialized levels of care (eg, neurologists, epileptologists) may also stem from a business perspective, as practices may

be concerned about losing patients to specialists.^{15,30} Financial incentives that support the appropriate referral of patients may lead to improved outcomes and care quality.

V. Bridging the gaps in epilepsy care

Many stakeholders are currently trying to address the continuity-of-care issues and gaps in epilepsy care, and these attempts take a variety of forms. Case management, improved data collection, and integrated healthcare systems have also been proposed as ways to improve the quality of patient care.

Case management

Case management is the timely coordination of quality services to address a patient's specific needs in a cost-effective manner.³¹ These services may be provided by nurse practitioners, hospitalists, and discharge planners—in addition to case managers.^{31,32} Case management services may include providing patients with social support services (addressing the stigma of epilepsy) and patient education and support (guidance on how to use seizure calendars and pill boxes), as well as ensuring the patient takes a more active role in their care planning.^{1,33}

Case management can have significant benefits for patients with epilepsy, including improved seizure control and quality of life.^{34,35} According to one study, the results of case management for patients with lower incomes are particularly significant. For these patients, case management was associated not only with improved control and quality of life, but also with significantly reduced emergency room visits.³⁴ These findings are particularly relevant for Medicaid Fee-for-Service and Managed Medicaid, which have higher prevalence rates of epilepsy.³⁶

Case management can play an integral role in improving care coordination, and may help reduce the total cost of epilepsy.

7 states' health departments or agencies have programs designed to improve care for patients with epilepsy. In Florida and Pennsylvania, these activities include case management services, such as epilepsy education and referral services.³⁷⁻³⁹ By studying these programs and analyzing which aspects work

well, other states may be able to implement similar programs to support patients with epilepsy.

Such programs also require increased funding and resources from state governments that may not recognize the issues faced by this patient population. Patient advocates can therefore support such efforts by raising awareness of the unique needs of these patients. Advocates can also help support existing healthcare programs that people with epilepsy rely on. For instance, the Epilepsy Foundation and its affiliates are involved in the Speak Up, Speak Out network, which follows national and state legislative activities to help protect programs vital to people with epilepsy.⁴⁰

Improved data collection

Epilepsy surveillance data can garner public and political support to fund interventions and then help measure their impact. It can show which major public health interventions are effective and which are not meeting expectations. Nevertheless, there is currently a lack of adequate epilepsy surveillance data and the infrastructure to accurately and thoroughly obtain such data.^{1,41} As part of the IOM's recommendations included within *Epilepsy Across the Spectrum*, the authors identified a need to strengthen the nation's data system. To accomplish this, the authors recommend the collection of epilepsy-specific data and collaboration with existing and emerging data-sharing efforts across healthcare providers and with other chronic diseases and disorders.¹ However, how to collect this data and more so how to make it actionable remain a question.

One leading example of how to integrate quality measurement and data collection into the current system is shown in a 2011 study published by Pugh, et al. The study assessed the quality of care for patients with epilepsy using quality indicator data from EMRs. Data from epilepsy-related medical visits in primary care and neurology clinics were then compared. The authors concluded that while it is indeed feasible to assess quality of care using such records, performance on quality indicators is suboptimal.⁴²

Collecting data longitudinally, via EMRs and registries, may help determine whether current process measures on the diagnosis of epilepsy lead to improved outcomes. Data collection can also help determine additional gaps in care.⁴² Furthermore, the implementation of quality indicators and measures attached to financial rewards for high performance (or penalties for low performance) can help improve care quality. However, it is also important to ensure these quality measures and indicators are linked to improved outcomes for patients with epilepsy.

It is necessary to create a system that incentivizes physicians to achieve higher quality care.

Integrated healthcare systems

While data collection and case management may be able to help patients currently receiving care, it is also important to ensure patients with epilepsy have access to the care they need. According to one study, health insurance and financial concerns may be barriers preventing patients from receiving a higher level of care. This may be because patients cannot afford out-of-network specialists, or cannot afford the medications prescribed by their physician.¹⁵

Newer, integrated healthcare delivery models may offer the possibility of improved patient access to specialists and support positive referral patterns. These models, which include accountable care organizations, integrated delivery networks, and patient-centered medical homes, aim to provide more coordinated and higher-quality care for patients with epilepsy. Moreover, such models may allow patients with epilepsy who suffer comorbid conditions more comprehensive management of their disease and its comorbidities.¹ This may include an increased availability of case managers from insurance companies and healthcare providers who can help patients navigate their responsibilities and rights.⁴³

More research should be done to assess if these new models translate into improvements in quality care, access, and outcomes.

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VI. Conclusion

Epilepsy is a common condition, affecting 2 million to 3 million Americans. These patients represent a particularly complicated population and face many barriers preventing them from achieving optimal care. One such barrier is the continuity-of-care issues faced by patients with epilepsy. Although patients with epilepsy require the care of numerous providers throughout their journey through the healthcare system, this care may be fragmented and suboptimal.

At the primary care level, increased support is needed to help providers who may not be familiar or comfortable with treating patients with epilepsy. Clearly delineating the roles of these providers and offering them the educational resources they need to manage their patients can improve the quality of care provided at this integral first step in the care continuum.

Moreover, there is still ambiguity among many pediatricians, primary care physicians, and even some neurologists regarding what constitutes uncontrolled seizures. Thus, there is a need to establish a standardized definition, which can lead to appropriate referral patterns. Educating physicians on the proper time to refer a patient and incentivizing these providers to do so can help ensure a patient receives the level of care they need.

This paper highlights several ways stakeholders are currently trying to improve the continuity of care for patients with epilepsy. However, these are only a small sampling of current quality initiatives. In order to better understand and address the barriers to optimal care, additional research, resources, and funding are needed.

VII. Disclosure

Dr. Ettinger received support for this article from Eisai Inc. He has served as a consultant on advisory boards to: UCB Pharma, Eisai Inc., and Upsher-Smith.

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