Using EHRs to advance epilepsy care

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Abstract

The improved use of Electronic Health Record (EHR) Systems provides an opportunity to improve the overall efficiency and quality of care of patients with epilepsy. Tools and strategies that may be incorporated into the use of EHRs include utilizing patient generated data, clinical decision support systems and natural language processing systems. Standardization of data from EHR systems may lead to improvement in clinical research through the creation of data collections and multi-center collaborations. Challenges to collaborative use of EHR Systems across centers include costs and the diversity of EHR systems.

The prevalence of epilepsy in the US population is 1.2%,¹ and there are 150,000 new cases of epilepsy every year.² Nearly 4% of people in the US will develop epilepsy in their lifetime.³ The burden of epilepsy comes not only from the direct effect of seizures but also from the comorbidities associated with the disorder and the indirect effect of lost economic opportunities for affected individuals and their caregivers.⁴ It is therefore important to develop and adhere to strategies that promote comprehensive patient centered care for epilepsy.

The increasing use of Health Information Technology systems has the potential to improve the delivery of healthcare in terms of cost savings, improved safety, and increased efficiency.⁵ Electronic Health Records (EHRs) are used daily by physicians and healthcare providers to care for patients. Between 2008 and 2014, the use of EHR systems increased dramatically, both by office based physicians (42%–83%) and hospitals (9%–76%) respectively.^{6,7} A recent review⁸ highlighted that the use of EHRs has the potential to improve adherence to quality measures for epilepsy that were developed by the American Academy of Neurology.⁹

It is within this context that a workshop on “Using Electronic Health Records (EHR) to Advance Epilepsy Care” was held in January 2017 at the Children’s National Health System in Washington, DC. The workshop brought together multiple stakeholders including clinicians, computational experts, parent advocates, and EHR vendors who are working towards using EHR to advance care in neurology. The aim of the workshop was to conceptualize the role of

Medical record

Stats and treatments

Treatment history

Telemedicine app

Remote Availability

Collaborative medicine

Remote access

Personal health records

Telemedicine

Children’s National Health System (JSM, MB, AB, BJ, GL, WDG), Washington, DC; Weill Cornell Medicine (ZMG), New York; Department of Neurology (RB), University of Virginia, Charlottesville; Alberta Children’s Hospital (JB), Calgary; Cerner Corporation (ZD, AG, LJ), Kansas City, MO; Cincinnati Children’s Hospital Medical Center and University of Cincinnati College of Medicine (TG), OH; Departments of Neurology and Pediatrics (HG), UVA Health System, Charlottesville, VA; RTI International (BK), Rockville, MD; Boston Children’s Hospital (TL), MA; NorthShore University Health System (DMM), Evanston, IL; and Ann and Robert H. Lurie Children’s Hospital of Chicago (DN), Northwestern University, Chicago, IL.

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the EHR to support quality of care, research, and technological innovation. The themes discussed regarding the use of EHRs could be broadly categorized into 5 main areas:

1. Patient generated data
2. Telemedicine opportunities
3. Decision support for physicians
4. Registries
5. Natural language processing
6. Multicenter data sharing and collaboration

Patient generated data

Patient generated data can include elements from the patient history and current symptoms. The data may be collected in real time or completed in advance and then made available to clinicians within the EHR system. The acquisition of data directly from the patient may save time during the clinic visit and ensure greater accuracy in the health records. The use of patient generated data may allow patients and their families to become more engaged in their care while enabling clinicians to improve efficiency during a clinic visit.¹⁰

Seizure frequency

Understanding seizure frequency is essential to clinical epilepsy care. This information may be collected through questionnaires or acquired from patient seizure detection devices. Several families use online seizure diaries (epilepsy.com; seizuretracker.com; texting4control.com; WebEase.org; patientslikeme.com), smart watches, and other devices to record their seizure data. The Responsive Neurostimulation System (a cranially implanted neurostimulator device used for intractable partial epilepsy) can remotely transfer seizure incidence data from a patient to a physician for potential therapy management.¹¹ Although many medical centers collect seizure frequency data generated by patients, it has been challenging to develop a system to automatically download the data into the EHR due to technical constraints. Potential barriers to patients or families completing the data prior to the visit include high completion rates include data complexity or primary language other than English. Nevertheless, completion of information prior to a visit is common practice in other disciplines (e.g., mental health, nutrition) and can be overcome with well-designed systems.¹²

Demographic and historical data

Some practices have patients provide information on portable electronic devices prior to being seen by the clinician. The information is then populated into the patient's health record and is available for the clinician to review during the visit and may therefore save time during the encounter.

Developmental and behavioral screens

Developmental and behavioral screens could be incorporated in the information collected prior to the visit while in the waiting room. A simple checklist completed by the parent may facilitate developmental screening in an epilepsy clinic with high sensitivity and specificity.¹³ With developmental and behavioral information available prior to a visit a physician may be able to identify and address comorbidities such as mood and anxiety disorders, attention deficit hyperactivity disorder, social problems or autistic spectrum disorders.

Telemedicine opportunities

EHR systems that allow exchange of information between clinicians and patients may facilitate telemedicine opportunities.¹⁴ For example, seizure tracking tools may allow clinicians to monitor a patient's health status in between visits for clinical decision making.¹¹ In addition, EHR integration of images or video may allow for remote care by specialists for acute or chronic conditions. The development of tools to promote telemedicine may be particularly valuable to increase access to pediatric neurology expertise, given the relative scarcity of pediatric epileptologists outside of major urban centers.¹⁵ Practitioners considering the use of telemedicine are now able to refer to guidelines through the American Medical Association,¹⁶ American Telemedicine Association¹⁷ and the Federation of State Medical Boards¹⁸ to evaluate compliance with state laws and regulations regarding telemedicine.

Physician generated data, structured data elements, and clinical decision support

One potential advantage of electronic documentation is clinical decision support (CDS) in which the EHR can provide real time advice to the clinician. CDS often requires physicians to use documentation tools that have structured data elements—i.e., questions with standardized answers, which allow the data to be easily queried, analyzed or adjusted within an electronic system.¹⁹ Examples of currently available discrete data elements in a medical record are height, weight and international classification of disease codes among others. Such data can be collected through the use of buttons and menus to input specified or limited ranges of responses to questions.

CDS may occur through computerized reminders (pop-up prompts) or generation of order sets.²⁰ Potential benefits of including CDS tools within an EHR system includes

One potential advantage of electronic documentation is clinical decision support in which the EHR can provide real time advice to the clinician.

enabling a physician to provide patient specific information at the point of care, avoid adverse events, and review actionable guidelines. EHRs with CDS tools need to be designed thoughtfully to avoid physicians ignoring prompts due to alert or physician fatigue.²¹

A recent report described how a set of structured clinical documentation support (SCDS) tools built within the EHR has been implemented in a large multi-subspecialty adult neurology practice.²² The SCDS tools capture several hundreds of fields of epilepsy data per office visit allowing standardization and improved quality of notes and improved quality of care by reinforcing adherence to best practices. The SCDS tools have also been used to support clinical practice and research with real time pop up prompts.²³ These SCDS tools that have been designed for adult populations may be used as a model for the research and development of similar tools specific for pediatric patients.

Data registries and collections

Data registries are collections of standardized information about people with similar conditions or diseases.²⁴ It is important to standardize clinical data collection to reduce variation between centers and physicians for the development of data registries. The National Institute of Neurologic Disorders and Stroke (NINDS) developed a set of common data elements (CDEs) for Epilepsy²⁵ for clinical research, these provide a useful reference for the standardization of data for patients with epilepsy. However, the NINDS CDEs for EEG and brain MRI results are binary or limited choices (e.g., seizure recorded vs not recorded) and may therefore need to be modified to make their use practical for clinical purposes.

When designing data elements for both clinical care and research, clinical practices have to weigh the instinct to collect a large amount of fine granular data with demands for efficiency. Consideration should also be given the data elements that would provide useful information at the individual as well as the group level to optimize the use of data collections and registries.

Pooling patient information into data registries or collections may help reveal group level data that may not be readily apparent at the individual level. To do this, EHRs can extract discrete data from administrative and clinical sources to create a “data warehouse.”²⁶ The information architecture

underlying a data warehouse is designed to support queries and analysis of populations; this is different than the architecture of a clinical EHR system designed to rapidly access individual patient information.²⁷

Data collections may remain HIPAA compliant and maintain privacy by excluding identifying information from the data collected. The data may be linked to identifiers that are stored in a separate secure database that is only accessible to selected individuals. To avoid identification of patients with rare conditions, databases may be set up to give results to a query in a summary format if those results would otherwise include a small number of patients.²⁷

Natural language processing for clinical decision support and research

Entering the information from a clinic visit as discrete data may necessitate the use of highly structured forms, however many centers continue to use free text information at the point of data entry (i.e., a clinic note). One of the principles of combining clinical care and research is to avoid duplicate data entry such as entering discrete data into a registry while separately completing a visit note into the EHR. Natural language processing (NLP), defined as the use of “computational techniques for the automatic analysis and representation of human language,”²⁸ can extract useful information from free text data. NLP systems provide an alternative to using highly structured forms or duplicate data entry. Retrospective studies using patients at a pediatric epilepsy center showed that patients’ free text clinical notes from the EHR could be processed with NLP using machine learning techniques to identify epilepsy surgery candidates by determining the risk of developing intractable epilepsy.²⁹ While this system has not yet been used for prospective clinical decision making, it lays the groundwork for the development of tools to make this possible. A study on the use of NLP for identifying patient cohorts within a large multicenter study investigating sudden unexpected death in epilepsy (SUDEP) demonstrated the possibility of developing a tool to identify cohorts with a high degree of specificity using data extracted from discharge summaries.³⁰ The development of cohorts using this tool could lead to the identification of risk factors for epilepsy sequelae (like SUDEP) or for targeted improvements in care.

Across center collaboration

Rationale for multicenter collaboration

Pooling patient data across centers results in larger patient populations and allows for improved understanding of the heterogeneity of disease. This is particularly important in pediatric epilepsy, considering that many of the conditions are rare. There are several models for how to leverage EHRs to support large research efforts while protecting patient privacy and abiding by HIPAA regulations.

Practice Based Research Networks

A Practice Based Research Network is a group of practicing physicians that collect data together to answer questions related to care delivery. An active neurology Practice Based Research Network has successfully shared EHR tools across multiple centers to pool data for 11 common neurologic indications.^{22,23} This initiative includes over 15 institutions whose pooled data are used for subgroup based adaptive assignment of treatments and captures outcomes data at the point of care using the EHR; for example, the treatments among 3 anti-epileptic drugs (AEDs) (lamotrigine, levetiracetam and valproic acid) with outcome measures of survival and 50% reduction of seizure frequency is being compared.

Prospective Registries

By pooling data from multiple centers and enrolling patients prospectively cohorts of patients with relatively rare conditions can be developed to allow for research that would not otherwise be possible at a single center. Infantile Spasms is an example of a rare condition where there is variability in initial treatment. Through the National Infantile Spasms Consortium database developed in 2012, the Pediatric Epilepsy Research Consortium determined that adrenocorticotrophic hormone was a more effective treatment than other standard therapies.³¹ Other examples of epilepsy specific prospective registries are the Pediatric Status Epilepticus Research Group's (pSERG) cohort that has been used to investigate variability in treatment of children with refractory status epilepticus³² and the Early Life Epilepsy Study which found that levetiracetam is superior to phenobarbital for new onset nonsyndromic epilepsy in infants aged 1 month to 1 year.³³

The use of multicenter collaboration and research to improve clinical care has been successfully demonstrated in other diseases by various groups. The Children's Oncology Group is an organization devoted to childhood and adolescent cancer research; they have a long history of clinical trials and collaborative research that has led to an overall significant increase in survival rates for childhood cancer.³⁴ Another collaborative group, the Vermont Oxford Network has used their Neonatal Encephalopathy Registry to investigate pertinent topics such as the antecedents of neonatal encephalopathy.³⁵

EHR Vendor Initiatives

Another initiative for collaboration across centers is the development of a pediatric epilepsy registry by the Cerner Corporation in collaboration with the Children's Hospital of Orange County and the Children's National Medical Center to close gaps in care and measure evidence based practices. The registry allows for assessing the adherence to best practice measures for epilepsy including the provision of annual emergency seizure action plans, reproductive health education for all females over 12 years of age and on AEDs, and surgical referrals for patients with intractable epilepsy (Z. Danner, personal communication, January 31 2017).

Common Data Elements

The NINDS CDEs provide a useful tool for collaborative research initiatives that utilize standardization of templates and data reporting. An essential need for data aggregation, however, is the development and implementation of CDEs that are clinically meaningful and feasible to be incorporated into clinical practice. A collaborative initiative by Nationwide Children's Hospital and the Children's Hospital of Philadelphia is working to develop a standardized template for EEG reporting within the EHR to standardize reporting and terminology, improve efficiency and billing as well as to facilitate collaborative research. An initiative such as this would benefit from the NINDS CDE module for scalp EEG which includes 105 distinct CDEs in discrete format covering breadth of details that would need to be included in a comprehensive EEG report. The NINDS Epilepsy CDEs include other modules for demographic, diagnostic, and therapeutic data elements that may be adaptable for practice.

Learning Healthcare Systems

In a Learning Healthcare System, clinicians enter data in a structured format at the point of care. These data are then aggregated, analyzed, and fed back to clinicians rapidly in order to improve care, for example through quality improvement projects or comparative effectiveness research. In pediatric epilepsy, there has been active work to measure quality of care for refractory status epilepticus by the pSERG.³⁶ Furthermore, a recent effort to develop a learning health care system is underway.³⁷ Several national efforts to standardize and share clinical data may help to provide the core informatics infrastructure for these initiatives, including public and commercial clinical health information exchange systems³⁸ and research based Clinical Data Research Networks Patient Centered Outcomes Research Institute's PCORnet infrastructure.³⁹

Barriers

There are multiple barriers and challenges associated with the adoption and use of the EHR systems discussed in this paper.

Resources

Several resources are required to create an effective EHR system that can simultaneously serve the clinical and research missions of a practicing pediatric epilepsy group. The modification of an existing EHR to include discretized data with CDS may require an intensive period of consensus building, content development, software EHR modification, and implementation into the clinical workflow.²² The costs associated with developing these systems may be prohibitive but may be overcome through sharing of existing tools between centers and joining already established data collection initiatives. Parent institutions could be incentivized to fund the development of the EHR systems within their Epilepsy Centers by the potential direct benefits including improvements in care navigation, more efficient note writing, timely

communications, value based payment, patient safety, quality improvement and others.²³ Additional sources of funding support that could be considered include the Small Business Innovation Research (SBIR) programs within the National Institutes of Health (NIH), the patient centered outcomes research institute (PCORI), or the Centers for Disease Control.

Collaboration across institutions

Institutions that are collaborating or sharing information have to agree on the terms and means of collaboration. Promoting buy in from other physicians and centers may present a challenge to building networks and data collection due to the natural question of “what’s in it for our institution?” An overall benefit of standardized data collection and recording is that it may lead to improvements in care and the ability to improve outcomes by enabling quality research. The use of commercial EHR systems, each with their own proprietary software and restrictions, across different institutions pose a challenge to collaboration. EHR toolkits for data sharing may be designed to work with different versions of the EHR (i.e., historical and current) to allow for broader implementation.²³ Data sharing between institutions using different EHR systems may be overcome through the development of platform agnostic data registries, i.e., registries that are easily accessible and usable by all EHR systems by using standard terminology equivalents. Overall, it would be more feasible to develop tools that may be used within existing EHRs across different institutions than to expect institutions to switch to a single EHR for collaboration. However, even with these modifications the data shared between systems may be limited and therefore the goals of collaborations have to be well defined. An additional challenge for existing EHR systems, is the changing concepts of epilepsy classification. The International League Against Epilepsy recently published a revised operational classification of seizure types⁴⁰; centers would need to ensure consistency in patient and cohort classification even with a potential change in description of the diagnoses.

Future directions

The stated goal that emerged from the conference was to ultimately develop “standard data collection to support research and quality patient care in epilepsy.”

At the conclusion of the workshop, action items under consideration included:

1. Developing a “common market” (shared resource pool) for sharing tools or data across groups
2. Using the collected data by participating centers to study rare epilepsy syndromes.
3. Applying predictive modeling techniques to EHR data in order develop, field test, and implement tools that identify high risk patients who may benefit from comprehensive epilepsy care

4. Developing platform-agnostic data registers to enable the sharing of data elements from different EHRs
5. Recruiting additional epilepsy centers, epileptologists and epilepsy related groups (such as the American Epilepsy Society) to the initiative being developed by the participants to the workshop.
6. Providing standardization of assessments and care through the review of existing practices for harmonization or development of new recommendations.

Meeting these goals will help the pediatric epilepsy community build their EHRs into useful tools to standardize practice, adopt common screening elements to identify and treat comorbidities, identify subpopulations who might benefit from targeted intervention, and provide a distributed engine for conducting clinical research. The rate of change in the development of EHRs may be slower than desired but its promise is so strong that it is worth the ongoing innovation, implementation and iteration until we see improved outcomes for our patients. Setting competitive goals now will help achieve major long term progress. Efforts that are already underway include the working pediatric epilepsy registry at the Children’s Hospital of Orange County and the Children’s National Medical Center, the neurology Practice Based Research Network through the Northshore University HealthSystem²³ and a pilot model for using basic CDEs in a learning healthcare system through Weill Cornell Medicine.³⁷ Staged advances through these efforts should be achievable within the next 2–3 years.

Conclusion

The incidence and burden of epilepsy in the US population necessitates the development and adherence to strategies promoting comprehensive patient centered care. The improved use of EHRs provides an opportunity to improve the overall efficiency and quality of healthcare through improved adherence to the AAN quality measures for Epilepsy and through enhanced research capacity. The National Institute of Neurologic Disorders and Stroke set of CDEs for Epilepsy provide a useful reference for the standardization of data to be collected for clinic visits for patients with epilepsy. Patient generated data that may be automatically uploaded to the EHR may save time and improve accuracy. The use of discrete data input by the physician during a clinic encounter may allow for standardization of information across patients and may also be useful in promoting the use of CDS within the system. NLP systems may extract useful information from free text data for clinical decision making and cohort identification. The creation of data collections and registries may help reveal patterns and characteristics about the patient populations that they serve. Multi-center collaborations can create larger population sizes for clinical research studies. Challenges to the standardization of EHR use include the large start up costs, lack of buy in from faculty, and the diversity of EHR systems in use across different centers. The potential for benefits ensuing from improved care, however,

is large. The systems and tools discussed in this report are applicable to the field of Neurology in general and most are not specific to epilepsy. Indeed, some of the collaborative initiatives referenced herein are not epilepsy specific. We believe the discussions and conclusions from our conference will be useful to general neurologists and subspecialists alike.

Author contributions

J.S. Mbwana played the primary role in drafting and revising the manuscript for content. Z.M. Grinspan, R. Bailey, M. Berl, J. Buchhalter, A. Bumbut, Z. Danner, T. Glauser, A. Glotstein, H. Goodkin, B. Jacobs, L. Jones, B. Kroner, G. Lapham, T. Loddenkemper, D.M. Maraganore, D. Nordli, and W.D. Gaillard contributed substantially to drafting and revising the manuscript for content.

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