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# Can big data help us close an epilepsy care gap?

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Epilepsy has been termed an “ambulatory care sensitive condition,” meaning that high-quality outpatient epilepsy care can reduce unnecessary emergency department (ED) visits and hospitalizations. Using this framework, high ED use is a marker of poor disease control or limited access to care.<sup>1</sup> Do all people with epilepsy (PWE) with poorly controlled disease or limited access frequent the ED? Are other factors at play? In this changing health care landscape, with accountable care organizations and a need to reduce costs, can we predict PWE who are at high risk of frequent ED use?

In this issue of *Neurology*®, Grinspan et al.<sup>2</sup> predicted frequent ED use in PWE through an innovative use of big data. Using a retrospective cohort analysis of administrative data from the New York Clinical Information Exchange (NYCLIX), a health information exchange network in New York City, the authors analyzed the predictors of frequent ED use in 8,041 PWE over 2 years. In bivariate analysis, adults (vs children and seniors), men, Manhattan residents (vs non-Manhattan), frequent users of health services, users of multiple health systems, and those with comorbidities in year 1 were more likely to have frequent ED use (4+ visits) in year 2 of the study. Despite examining numerous statistical models to predict frequent ED use in year 2, the authors found that a simple one-variable logistic regression model, based on the number of ED visits in year 1, performed comparably. Simply put, baseline ED use predicted follow-up ED use. PWE with heavy ED use (11+ visits) in year 1 had a  $\geq 50\%$  probability of frequent ED use in year 2. The authors predicted future frequent ED visits with high accuracy (area under the receiver operating curve  $>0.85$ , positive predictive value  $>70\%$ ) but with poor sensitivity (approximately 20%). Although easy to identify a group of PWE at high risk of frequent ED use, it is still difficult to predict ED use for most PWE.

Innovatively, the authors used big data to identify PWE at high risk of frequent ED use. By linking patient records from 7 of 13 Manhattan emergency

departments, the authors were able to evaluate two-thirds of Manhattan’s yearly ED visits. By connecting unaffiliated institutions, the authors determined that PWE who used multiple health systems (vs one system) in year 1 were more frequent ED users in year 2. Because PWE can have seizures at the most inopportune times, it is not surprising that some PWE use multiple different unaffiliated EDs. Although comprehensively examining numerous predictive models, a simple one-variable logistic regression model was the most parsimonious.

Unfortunately, big datasets often come with missing information. The authors identified PWE using a “probable epilepsy” algorithm defined by an *ICD-9* code of 345.x (epilepsy) or 2 codes of 780.39 (convulsions) on separate days.<sup>3</sup> Different validated epilepsy algorithms, including both *ICD-9* codes plus antiseizure medications, have been used to analyze veterans administrative data.<sup>4</sup> The authors were not able to validate their definition, making it likely that a proportion of their cohort included some people without epilepsy (e.g., patients with provoked seizures only, or nonepileptic seizures). Such codes also lack reliable information about disease severity and epilepsy type. Because of limitations in the NYCLIX database, a number of other factors—such as race, ethnicity, socioeconomic status, insurance type, or whether the person had a regular epilepsy source of care and with whom (primary care, neurologist, epileptologist)—were not included in the prediction models. In the Houston/New York City health care use study, black and Hispanic patients with epilepsy had higher rates of generalist visits, emergency room (ER) care, and hospitalizations, and lower rates of specialist visits<sup>5</sup>; and over time, patients with a low socioeconomic status had higher use of the ED.<sup>6</sup> Furthermore, such NYCLIX data do not measure factors such as whether a seizure took place in public, stigma, or utilization of self-management strategies.<sup>7,8</sup> While Grinspan et al. demonstrated that high ED use predicts future ED use, we are still left not fully knowing whether, and the extent to which, health disparities, a

See page 1031

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lack of regular access, and poorly controlled disease are predictive of future ED use in PWE.

The recently passed Medicare Access and CHIP Reauthorization Act of 2015 provides incentives for physicians to participate in Alternative Payment Models (APMs). APMs will discourage high-cost, high-volume, procedure-laden care delivery such as is typically provided by frequent ER visits and hospitalizations, making predictive modeling of high and low ED utilizers important. Furthermore, ED visits for PWE have potential financial and health-associated costs; the health risks of repeated radiation exposure associated with repeated CT testing for PWE in the ED are not inconsequential. Just as important as the high utilizers, this study identified a subgroup of high utilizers in year 1 who reversed this pattern in year 2. What are the characteristics of this population that led to a reduced utilization? Can these characteristics be used in an intervention strategy for other high utilizers?

Utilizing administrative data from a health information exchange network covering 7 of 13 ERs in Manhattan, Grinspan et al. found that a one-variable logistic regression model worked equivalently to more complicated analytic models to predict frequent ED use in PWE over 2 years, once again demonstrating Occam's razor that simple is often best. This work is foundational to the paradigm shift in health care payment policy, where the ability to identify specific populations to target for focused interventions will be essential to changing health care consumption and outcome. This work, however, is only the first step. Changing behavior will rely on identification of characteristics of the high and low utilizers that might be amenable to future intervention strategies aimed at selectively targeting patients at high risk—and ultimately aligning unaffiliated

systems such that high-risk patients can be identified at the point of care.

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