



Improving Patient-Centered Care Coordination for Children With Epilepsy: Version 2.0 Upgrade Required

Assessing Systems of Care for US Children With Epilepsy/Seizure Disorder.

Kenney MK, Mann M. *Epilepsy Res Treat* 2013;2013:1–11.

BACKGROUND: The proportion of US children with special health care needs (CSHCN) with epilepsy/seizure disorder who receive care in high-quality health service systems was examined. **METHODOLOGY:** We analyzed data for 40,242 CSHCN from the 2009–2010 National Survey of CSHCN and compared CSHCN with epilepsy/seizure disorder to CSHCN without epilepsy/seizure disorder. Measures included attainment rates for 6 federal quality indicators with comparisons conducted using chi square and logistic regression methods. In addition, CSHCN with epilepsy/seizure disorder were compared to CSHCN without epilepsy/seizure disorder on the basis of 14 unmet health care needs. **RESULTS:** Lower attainment rates for receiving comprehensive care in a medical home and easily accessible community-based services were found for CSHCN with epilepsy/seizure disorder versus CSHCN without epilepsy/seizure disorder (medical home: 32% versus 43%; accessible community-based services: 50% versus 66%, resp.) in unadjusted analyses. Lower adjusted odds for these indicators as well as greater unmet need for specialists, dentistry, prescriptions, therapies, and mental health care were also found for CSHCN with epilepsy/seizure. **CONCLUSIONS:** Further efforts are needed to improve attainment of high-quality health care services for CSHCN with epilepsy/seizure disorders.

Commentary

Children living with active epilepsy experience more anxiety, depression, conduct problems, learning disabilities, less knowledge of epilepsy and its management, and greater perceived epilepsy-related stigma (1, 2). In addition, a large proportion of both children and adults in the United States with uncontrolled or refractory epilepsy are more likely to be uninsured, to have lower socioeconomic status, and to live in rural communities (3, 4). Furthermore, while about 20% of Americans live in rural areas, only 9% of the nation's physicians practice in these areas. Such disparities in this vulnerable population impact the ability to self-manage ongoing care needs and adhere to prescribed therapies, leading to increased utilization of urgent healthcare resources, such as emergency departments (5–7). These inequities highlight the need for efficient coordination of scarce resources, including 1) epilepsy subspecialty medical care, 2) complementary mental health services for patients with comorbid psychiatric disorders, and 3) community-based social services to accommodate a significant portion of this population.

The recent study by Kenney and Mann (2013) provides a retrospective analysis demonstrating that children with special health care needs (CSHCN) and active or current epilepsy (CE), receive inadequate comprehensive care management

compared with CSHCN without such a diagnosis. The authors examine whether the benchmark recommendations published by the Institute of Medicine (IOM) are being met for providing comprehensive care to CSHCN with CE. These recommendations include a medical home mechanism where robust connectivity to community-based resources is crucial for providing comprehensive care. Such a scenario is also consistent with a patient-centered population health management (PHM) approach not explicitly stated in the article. The goal of PHM in this context is to significantly modify morbidity patterns by reducing health inequities among CSHCN with CE compared with CSHCN without CE.

To address the limited access of this population to complementary community-based services across care domains, models must be designed to employ scalable technology-based patient- and family-centered care coordination. An emphasis must be placed on a collaborative team approach for coordination of specialized medical needs and psychosocial services. Such care models can potentially prevent emergency department visits and maintain these individuals in lower-cost ambulatory settings, including rural healthcare clinics, Federally Qualified Health Centers, mental health clinics, and community social service agencies.

A patient-centered philosophy is integral to successful deployment of medical home and PHM strategies and is beginning to drive health reform–related payment incentives. The IOM describes patient-centered care as that which “is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide



all clinical decisions" (8). Emerging remote telehealth access in the medical home and PHM concepts is considered an important component of addressing both patient-centered care and collaboration between providers. Telehealth can be variably defined but fundamentally includes video-conferencing capability (telemedicine) coupled with coordinated care services. Utilization of such information technology (IT) will enable patients to consult with specialists at tertiary care medical centers while efficiently interfacing with on-demand community-based "wraparound" psychosocial services. It is important to emphasize that telehealth is not the treatment, but rather a bridge possessing the capability of connecting resources with the patient in near real-time (9). The authors emphasize access to community-based coordinated care services. Emphasizing IT-assisted care coordination for CSHCN with active or current epilepsy will increase access and coordinated referrals to medical, mental health, and social services.

The cost of such comprehensive care coordination that can result in improved patient outcomes remains uncertain as does the size of the patient load that can be managed by a given team of providers and collaborating coordination agencies. This financial burden will increase dramatically following full implementation of the Patient Protection and Affordable Care Act, when 18.2 million of the estimated 48 million uninsured individuals will acquire healthcare coverage (10). Increased efficiencies in healthcare delivery are urgently needed to enable limited resources to provide care for a large number of new patients, including those without coverage but potentially eligible for some form of government assistance.

Utilization of PHM can potentially facilitate both prospective monitoring and effective interventions to efficiently address the large number of CSHCN with medically refractory epilepsy and comorbid conditions, such as developmental disabilities and mood disorders. PHM is currently in its infancy, and it is not clear whether PHM initiatives can reliably deliver better health outcomes. Researchers have not yet identified a set of effective methods for improving the health of whole populations, short of community-wide public health campaigns. This observation suggests that when large organizations choose to pursue a PHM initiative, close monitoring and evaluation will be critical to guide its evolution over time to maximize favorable outcomes. Furthermore, telehealth has been only recently shown to be effective in coordinating healthcare and saving time in areas where service access is scarce. However, there is a lack of data showing that telehealth services improve outcomes. The IOM has recently called for more evidence on telehealth outcomes regarding healthcare status.

Kenney and Mann outline the limitations of their study, including the telephone survey mechanism by which data were collected for the CSHCN National Survey Instrument. Of importance, case status for CSHCN with current epilepsy was determined by parent report. The definition of CE assumes active epilepsy. In fact, such a lack of objective criteria for reporting cannot delineate refractory epilepsy or even repre-

sent active epilepsy at the time of reporting. In addition, the measurement of the unmet need was not based on an objective standard. The authors suggest that innovative strategies, such as medical homes, are critical for improving collaborations between providers and community services. In particular, connectivity-intensive outreach management mechanisms are required. For example, provider access to innovative IT communication protocols designed to quickly coordinate community-based social services and subspecialty care will challenge the current standard-of-care approach for evaluating and following CSHCN. Overall, this important study underlines the inadequacies in comprehensive care coordination for children with special health care needs and a diagnosis of epilepsy. The efficient bridging of medical providers with community-based services remains an unmet need. Further development of innovative high-quality care models for underserved vulnerable populations is necessary for effective implementation of healthcare reform.

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