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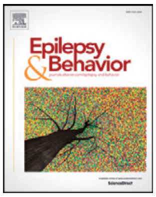

Editorial

Editorial on “Current behavioral health screening practices in pediatric epilepsy, by Wagner et al. (this issue)”☆

In 2018, the Epilepsy Foundation was awarded a The National Patient Centered Clinical Research Network (PCORNet) Learning Health System Network Pilot Collaborative grant to establish an Epilepsy Learning Healthcare System (ELHS). The mission of the ELHS is to design and implement a system that will improve outcomes for people with epilepsy and their families and caregivers by improving quality of life, seizure control, and seizure freedom. The impetus behind the Learning Health System is to involve family, community, clinicians, researchers, and health system leaders to design and implement collaborative research and quality improvement efforts. The primary intent of the ELHS is to work towards better health outcomes with increased quality and valued care. The ELHS will focus on accelerating the generation of new knowledge and disseminating the new information to the field in order to put it into practice in a timely and efficient manner (Epilepsy Foundation https://www.epilepsy.com/make-difference/epilepsy-learning-healthcare-system-elhs) [1].

It is in the context of initiatives like the ELHS that Wagner et al. conducted a survey of epilepsy health care professionals to characterize the behavioral health and cognitive screening practices in pediatric epilepsy in 24 epilepsy programs across the United States. The intent of this study was to inform the development of guidelines for behavioral healthcare for children with epilepsy. Additionally, the findings will be utilized to educate providers, to develop standardize behavioral health screening practices, and to ultimately share behavioral healthcare outcomes system wide.

As is noted by the authors, a number of behavioral and cognitive initiatives have been supported by the International League Against Epilepsy (ILAE) [2–4], American Epilepsy Society (AES) [5], and American Academy of Neurology (AAN) [6]. These initiatives have advocated that routine screening, referrals, and treatment of behavioral and cognitive problems should be an essential element of epilepsy care for children and adults. Despite repeatedly highlighting this need, there remains a gap between knowledge and implementation of system-wide guidelines and treatment initiatives. Neurologists and neuropsychologists are integral providers in epilepsy care, but frequently behavioral health providers, including clinical psychologists and psychiatrists, are not a part of the epilepsy care team. Neither screening measures nor evidenced-based treatment interventions are systematically recommended, leading to more confusion in the field regarding which measures to utilize, how to bill for screening appropriately, and even where to send referrals. There are no system-wide initiatives to recruit behavioral health providers to the field of epilepsy or to determine if epilepsy-specific evidence-based interventions are needed to treat the behavioral and cognitive consequences of epilepsy.

In 2012, the Institute of Medicine [7] recommended routine behavioral health screening to be included in epilepsy care; however, the results of this survey by Wagner et al. found that only 19–27% of the respondents were systematically screening children with new onset epilepsy, and only 10% were screened annually. Additionally, there was significant variability in the screening methods and tools that were utilized.

The results of the survey are somewhat surprising given the increased attention that behavioral and cognitive complications have received over the last decade. Screening tools have been developed, and common data elements have been identified to improve the sharing of data across epilepsy centers. However, there is no consensus regarding standards of practice including recommended screening tools, treatment modalities, and ongoing monitoring of these significant behavioral problems often associated with quality of life and even seizure outcomes among children with epilepsy. The authors suggest including behavioral health providers (e.g., clinical psychologists) as integral members of the epilepsy care team, as well as utilizing a 3-tier screening approach that could be studied across multiple epilepsy centers to determine its effectiveness and impact on behavioral outcomes.

As a field, it is important to be reminded that solely recognizing that behavioral and cognitive complications are common in epilepsy does not in and of itself lead to resolution of the problem. The field of epilepsy will need to continue to support the establishment of standards of care that identify mechanisms in the epilepsy healthcare system to screen for and adequately treat the associated complications of epilepsy that have been identified to negatively impact children and families that care for them.

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☆ The author, Jana E. Jones, PhD, reports no conflict of interest with reference to this work.

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