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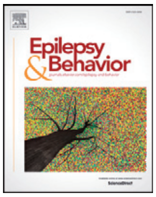

Brief Communication

Current behavioral health and cognitive screening practices in pediatric epilepsy

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ABSTRACT

Purpose: Initiatives such as the Epilepsy Learning Healthcare System continue to advocate for standardized care and shared outcome data. Therefore, the current project aim was to gather information from epilepsy healthcare professionals, behavioral health professionals in particular, regarding their behavioral health and cognitive screening practices in pediatric patients with epilepsy. Information obtained will be used to assist in the development of new educational programs and platforms in the American Epilepsy Society (AES) and to inform the development of guidelines for behavioral healthcare of patients with pediatric epilepsy.
Survey information: Twenty-five AES members representing 25 unique epilepsy programs across the United States participated in the survey. Findings are described in terms of three focus areas: (1) Systems, (2) Assessment, and (3) Intervention. Over 80% of respondents surveyed reported that they do conduct formal screenings, most commonly to determine if further evaluation is indicated (81%), inform treatment decisions (57.1%), and for developmental surveillance (33.3%). Assessment methods were fairly evenly split between nonstandardized informal questions (50%) and evidence-based broadband measures, with the Behavior Assessment System for Children (BASC), 2nd or 3rd Editions (40%) most commonly used. If behavioral health concerns are identified, referrals are often made for psychotherapy (48% in-house; 80% community-based), psychiatry (68% in-house; 48% community-based), and cognitive testing (88% neuropsychological testing; 36% for psychoeducational testing). Thirty-two percent refer for psychotropic medication management.
Conclusion: According to this survey, a number of epilepsy centers and clinics incorporate behavioral health screening; however, there is significant variability in assessments/measures used, who is administering them, and their purpose in the trajectory of treatment. These findings emphasize the need for standardization across centers in order to most effectively provide comprehensive care for youth with epilepsy.

1. Introduction

Children with epilepsy are at high risk for behavioral health (i.e., social, emotional, and behavioral functioning) and cognitive comorbidities [1,2]. In the past 5 years, several task forces and committees of the International League Against Epilepsy (ILAE), American Epilepsy Society (AES), and the American Academy of Neurology (AAN) have recommended routine screening of behavioral health and cognitive comorbidities associated with epilepsy [3–6]. In fact, routine screening of these comorbidities is an important part of comprehensive epilepsy care but does not occur in most pediatric epilepsy centers despite consensus statements and recommendations for screening practices, including the use of validated screening instruments, developmental considerations, multiple informants, and triage [7–12].

These most recent consensus statements have not included recommendations for the use of specific measures. However, several reliable and valid screening instruments exist to measure a variety of behavioral health and cognitive symptoms, including the Pediatric Symptom Checklist-17 [13], Strengths and Difficulties Questionnaire [14], Neurological Disorders Depression Inventory-Epilepsy for Youth (NDDI-E-Y) [15], Children's Depression Inventory-2 (CDI-2) [16], and CNS Vital Signs [17]. Many of these instruments have been used and/or validated in pediatric populations with epilepsy [15,18–21]. Nonetheless, it is unclear what, how, and when pediatric epilepsy centers use these screening instruments in clinical practice.

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The purpose of the current study was to survey AES members at pediatric epilepsy centers and clinics across the United States to better understand if behavioral health and/or cognitive screening occurs, who (i.e., which medical professional) conducts the screening, which instruments are utilized, and the frequency of screening. In line with the Epilepsy Learning Healthcare System, a system in which best practices are seamlessly embedded in the epilepsy care process, this information can be used to educate providers, standardize behavioral health practice, and promote sharing of data outcomes to evaluate patient, provider, and healthcare systems outcomes [22].

2. Survey development and dissemination

Members of the AES Interprofessional Education Committee (IEC) and the Pediatric Epilepsy Research Consortium (PERC) Behavioral Health Group designed a survey to gather information from behavioral health professionals (e.g., psychiatrists, psychologists, neuropsychologists, social workers) regarding their behavioral and cognitive screening practices in youth with epilepsy. An invitation to create the survey was extended to all members of the IEC and PERC, and interested individuals were active in the creation of the survey. The survey went through an iterative process based on feedback via phone conferences and email exchanges, resulting in a final 25-item survey (see Table 1). This final survey was reviewed and approved by the AES Council on Education.

The survey was then constructed in SurveyMonkey [23]. The option was chosen to disable internet protocol (IP) address tracking to ensure survey responses were anonymous. Consultation with an Institutional Review Board (IRB) resulted in classification of this project as a Quality Improvement project designed to help inform the creation of future resources within the AES and, therefore, did not require IRB approval as a human subjects study.

Table 1
Survey questions.

1 Is your site an epilepsy center as defined by the National Associations of Epilepsy Centers (NAEC)?
2 What is the name of your site (e.g., institution/practice)?
3 What type of professional are you?
4 If you are a psychosocial provider, do you belong to any of the following groups? Please check all that apply.
5 Indicate what behavioral health professionals are at your site. Check all that apply.
6 What company does your site use for electronic medical records?
7 Does your site screen patients for behavioral health and/or cognitive symptoms?
8 What technology is utilized or available at your site when screening patients for behavioral health concerns? Check all that apply.
9 What assessment measures are used behavioral health screening at your site? Check all that apply.
10 What is the purpose of the behavioral health screen? Check all that apply.
11 What assessment measures are utilized for cognitive screening at your site? Check all that apply.
12 What is the purpose of the cognitive screen? Check all that apply.
13 Who administers the behavioral health or cognitive screening instruments? Check all that apply.
14 What methods are utilized for scoring behavioral health and cognitive screening instruments? Check all that apply.
15 At your site, who is identified for behavioral health/cognitive screening? Check all that apply.
16 Where and when are behavioral health/cognitive screens conducted? Check all that apply.
17 How often do you screen patients for behavioral health concerns? Check all that apply.
18 Who reviews screening measures and discusses results with the family? Check all that apply.
19 Have you ever experienced issues with copyright law with using electronic versions of assessment measures or in other ways?
20 At your site, how are you reimbursed for behavioral health/cognitive screening services? Check all that apply.
21 When patients are identified to have behavioral health and/or cognitive concerns, what services do you typically recommend? Check all that apply.
22 If you recommend psychotropic medications, to what professionals do you refer patients for medication management? Check all that apply.
23 How are epilepsy clinics (visits) staffed at your site? Check all that apply.
24 How are behavioral health services funded? Check all that apply.
25 Are you conducting behavioral research at your site?
26 Thank you for your participation in this survey. Please include any additional comments you feel are pertinent for us to know.

As the survey was developed by an AES committee and to inform AES future projects, the survey was disseminated via AES electronic newsletters sent on October 3rd, 17th, and 31st, 2017 with this description:

> “The AES Interprofessional Care Committee has jointly, with the Pediatric Epilepsy Research Consortium Behavioral Health Group, designed this survey to gather information regarding behavioral health screening practices to inform best practices in assisting patients with co-morbid behavioral health needs. If you have a psychiatrist, psychologist, neuropsychologist or social worker at your site, please ask that person to complete this survey. If you do not have a designated behavioral health professional, please take a few moments to respond to the best of your ability.”

Once providers clicked on the survey link, further instructions were provided:

> “Please complete only one survey for your site. For each question, please choose all options that apply. For the purposes of this survey, behavioral health refers to the assessment (including screening) and treatment of social, emotional, and behavioral functioning in children and adolescents with epilepsy. When answering, consider only behavioral health clinical services provided at your site for pediatric patients with epilepsy only.”

In an attempt to obtain more responses, in February of 2018, several Special Interest Groups (Psychiatry, Cognitive & Behavioral Treatments, Nursing,) through AES Connect communities were targeted. These additional instructions were provided:

> “If you completed a survey in October, please do not respond again this time.”

3. Findings

Twenty-five individuals representing 25 epilepsy programs across the US participated in the survey. Ninety-six percent of respondents reported that their epilepsy program meets criteria set by the National Associations of Epilepsy Centers [24]. Findings are described in terms of three focus areas: (1) Systems (e.g., site characteristics, behavioral health professionals), (2) Assessment (e.g., measures/tools used), and (3) Intervention (e.g., referrals). Respondents were mostly neuropsychologists (40%) and neurologists (28%). Pediatric psychologists (20%) and social workers (8%) were less likely to be a respondent to the survey, along with another 4% marking “Other”.

3.1. Systems information: who, when, where, why, & how

3.1.1. Why

Eighty-four percent of clinics surveyed conduct formal screenings. Respondents indicated that the purpose of screening was to identify the need for further evaluation (81%), inform treatment decision-making (57.1%), developmental surveillance (33.3%), follow patients in clinic (23.8%), and other (14.3%).

3.1.2. Who

As outlined in Fig. 1, neuropsychologists (96%), social workers (96%), neurologists (92%), and pediatric psychologists (72%) were the most commonly identified specialists providing behavioral health services. In terms of who administers the behavioral health screening, neuropsychologists and neurologists (42.9%) were the most commonly identified professionals, followed by pediatric psychologists (23.8%) and nurses

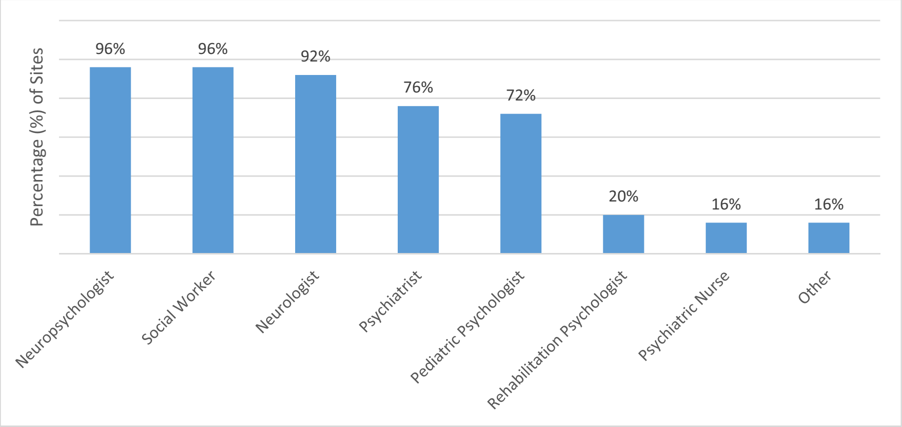

Fig. 1. Providers involved in behavioral healthcare for pediatric patients with epilepsy.

(28.6%). In addition, sites frequently use psychology fellows (57%). Social workers were not identified as personnel who conduct screening. Again, neurologists (54.6%) and neuropsychologists (45.5%) were identified as also reviewing screening data and discussing results with patients, along with 31.8% of sites indicating clinical psychologist involvement in reviewing and discussing screening results. Less common were nurses (18.2%), graduate students in psychology (13.64%), and social workers (9.09%).

3.1.3. When

Regarding screening approaches, a majority of respondents (54.6%) reported that medical providers identified “at-risk” patients, who were then administered behavioral health screeners. In approximately one-third of programs (36.4%), all patients are screened, and another 27.3% of programs made referrals to specialty behavioral health clinics. Medication nonadherence (27.3%) and newly diagnosed epilepsy (27.3%) were also identified as reasons for screening at some sites. Of those programs that conduct routine screening, 65% of sites screen before the patient is seen by the medical provider (e.g., provided a questionnaire during check-in). A majority of programs (42.9%) relied on consultations initiated by the medical team whereas about a third (38.1%) of programs screen patients during every clinic visit and 19.1% only when newly diagnosed with epilepsy. Only 9.5% conduct annual screenings. Of note, these percentages contain overlap (e.g., sites who screen at every visit may have also endorsed annual screenings).

3.1.4. Where & how

In addition, a variety of methods and measures are used to screen for behavioral health concerns. The majority of centers (61.9%) utilize paper/pencil screening forms, with 28.6% using tablets (e.g., iPads). Interestingly, 9.5% conduct online surveys prior to the clinic appointment, and 4.8% conduct telephone surveys. Fourteen percent do not utilize any form of technology when screening for mental health concerns. Almost half utilize computer scoring (47.6%), and 38.1% rely on hand scoring methods. Only 14.3% of respondents use tablets to administer and score, with 14.3% utilizing electronic medical record (EMR) scoring assistance. Of note, 23.8% of programs surveyed manually review critical items (e.g., suicidal ideation) only. For those using EMRs, most programs (60.9%) did not report barriers with copyright laws related to screening measures being integrated in the medical record.

All programs report using EMR systems, with *EPIC* (56%) being the most common. Other systems include *Cerner* (16%), *Allscripts*, (8%), *eClinical Works*, and *Nextgen* (each 4%). Approximately 8% indicated other EMR systems, in particular, internal documenting systems, but several respondents noted a current transition to *EPIC*. Regarding billing codes, half of programs do not bill and/or use specific billing codes (50%), but 30% use International Statistical Classification of Diseases and Related Health Problems (ICD-10) codes, and 20% use health and behavior codes and psychotherapy codes. Sixty-eight percent reported that their program's behavioral health services are funded through billing. (Of note, this information was gleaned from a separate question than the question inquiring about specific billing codes.) Institutional support was the second most common source of funding (36%), and a few respondents endorsed grant support (12%).

3.2. Assessment information: the “what” component

Assessment methods were fairly evenly split between nonstandardized informal questions (N = 10; 50%) and evidence-based broadband measures. Of the validated broadband measures (see Table 2), the most commonly used was the Behavior Assessment System for Children (BASC), 2nd or 3rd Editions followed by the Conners' Rating Scales. Measures assessing specific domains were also relatively common, with the CDI-2 as the most frequently used, followed by the Multidimensional Anxiety Scale for Children (MASC). Quality of life measures were also used, such as generic (e.g., PedsQL; N = 6; 30%) and epilepsy-specific measures (e.g., Quality of Life in Childhood Epilepsy (QOLCE) and Quality of Life Inventory for Epilepsy-48-Adolescent (QOLIE-48-A); N = 5; 25%).

3.3. Treatment information

If behavioral health concerns are identified, referrals are often made for further assessment and treatment. The most commonly identified referrals were for psychotherapy (48% in-house; 80% community-based), psychiatry (68% in-house; 48% community-based), and cognitive testing

Table 2
Assessment measure used across epilepsy centers.

Measures	Number of sites	Percentage of sites
Broadband measures		
Behavior Assessment System for Children (BASC), 2nd or 3rd Editions	8	40%
Conners' Rating Scales	6	30%
Vanderbilt Assessment Scales	5	25%
Achenbach Child Behavior Checklist (CBCL)	4	20%
Specific measures		
Children's Depression Inventory-2 (CDI-2)	7	35%
Multidimensional Anxiety Scale for Children (MASC)	5	25%
Patient Health Questionnaire-9 (PHQ-9)	3	15%
Quality of life measures		
Generic quality of life measures	6	30%
Epilepsy-specific quality of life measures	5	25%

(88% neuropsychological testing; 36% for psychoeducational testing). Thirty-two percent refer for psychotropic medication management. Of those psychotropic medication referrals, all respondents reported that they refer to psychiatrists but also may direct patients to their pediatrician (48%), primary care practitioner (PCP; 24%), developmental/behavioral pediatrician (40%), or are managed by the epilepsy provider (28%). Additionally, patients may be directed to other local community resources such as faith-based support (28%) or national organizations like the Epilepsy Foundation (48%) for information and resources. Supplements (e.g., vitamin B6) to address mood concerns are also recommended on occasion (8%).

4. Discussion

It is well established that screening for behavioral health concerns should be a routine part of comprehensive epilepsy care for children and adolescents with epilepsy [21]; however, a gap between recommendations and practice persists. Therefore, the current project was an initial attempt to understand current screening/assessment practices among AES members in pediatric epilepsy centers and clinics. Our data provide valuable insight into the current practices of psychosocial screening among the centers that chose to respond to our survey. It is clear from our data that there is huge variation in the who, what, when, and how of psychosocial screening in youth with epilepsy (YWE) and that the field may benefit from more clear guidelines regarding best practice.

Regarding systems-oriented factors, our survey suggests that neuropsychologists, neurologists, and psychology postdoctoral fellows were the most common members of the team to administer behavioral health screening, with a similar frequency across these disciplines. Neuropsychology and neurology were the two disciplines who were most likely to review these results with families. Notably, the questions regarding administration and reviewing covered both behavioral health and cognitive screening; therefore, we are unable to determine how many providers answered this for primarily behavioral health or neurocognitive screening or both. Some sites may also have reported both — a neuropsychologist for cognitive screening and a psychologist for behavioral health screening. In any case, these findings suggest the need to integrate more behavioral health specialists into the epilepsy healthcare team as only a quarter to a third of programs reported psychologists (nonneuropsychologists) engaged in administration and review of screening. Psychologists have expertise in behavioral health interventions and could provide the continuity of care from screening to intervention dissemination. Indeed, Guilfoyle and colleagues provide support for the feasibility and effectiveness of integrated behavioral health service within routine epilepsy care that includes screening, preventative care, and brief behavioral health intervention to target clinical symptoms [25].

The most common reason for screening was to identify the need for further evaluation of emotional/behavioral concerns. Despite recommendations from the Institute of Medicine to incorporate behavioral health screening into routine epilepsy care [26], only 19–27% of respondents indicated that all patients with a new diagnosis of epilepsy are screened, and only 9.5% indicated that this screening is repeated annually. Therefore, even among centers who routinely screen for behavioral health concerns in YWE, there are likely many patients who are not being screened or who may have significant behavioral health concerns that develop after the initial screening is completed [21]. This is underscored by the fact that the majority of centers screen on an as-needed basis following identification of concerns by the medical team. Most centers continue to use traditional paper/pencil assessments. Given that all respondents indicate the use of an EMR system, it is likely that respondents are underutilizing technology that may make routine screening easier.

There was significant variability in the assessment methods being used. Fifty percent of respondents indicated that they are using informal/nonstandardized methods of screening. This is notable because research has shown that identifying behavioral health concerns based on various levels of structure in assessment (e.g., diagnostic interview versus screening instrument) yields different results [27]. Furthermore, some institutions are using screeners that are not diagnostic (i.e., the Patient Health Questionnaire-9 (PHQ-9)) while others are using broad-based tools that identify a variety of emotional and behavioral concerns that can aid with diagnosis (i.e., BASC, Achenbach systems). The variation in assessment techniques makes it difficult for collaboration across clinical sites and may contribute to a patient being identified with behavioral concern at one site but not another, creating discrepancy in prevalence-reported rates. Additionally, referral for additional behavioral health intervention may be contingent upon screening tool and treatment site. More recent consensus statements have focused on screening practices but have not included recommendations for specific screening measures [4,6,11,12]. Presently, the epilepsy common data elements are available to inform choice of behavioral health assessment at clinical sites. Indeed, these common data elements were compiled to assist with research study design; however, many of the behavioral health measures are intended for clinical use (e.g., CDI-2 [28]). Further, there is a strong body of research providing support for the use of some of these standardized measures in clinical practice with pediatric populations with epilepsy (i.e., Children's Depression Inventory, Behavioral Assessment Scale for Children, and Pediatric Symptom Checklist) [18,21,25].

All respondents reported referring for additional behavioral health support or treatment when an emotional or behavioral concern is identified. Some institutions refer to mental health providers within their organization while others use community-based resources or local organizations (e.g., Epilepsy Foundation, faith communities). Wide variation in referral options is to be expected based on the nature and severity of the concerns being identified. It is helpful to gain an understanding of the variety of treatment resources utilized across institutions in order to improve access for YWE to much needed support for behavioral health concerns. Notably, patient and caregiver psychosocial care needs and behavioral health symptoms change over the course of epilepsy treatment [29], and it is important for clinics to consider the resources available in their communities. National Initiatives, such as the National Coordinating Center for Epilepsy through the American Academy of Pediatrics is working to better educate pediatricians about epilepsy and behavioral healthcare in pediatric patients with epilepsy as well as to provide resources for primary care providers [30]. In addition, efforts within the AES have been focused on creating pediatric psychosocial screeners and handouts on anxiety and depression in an effort to equip providers with educational resources to inform their clinical care [31].

Another systemic consideration for the feasibility of behavioral health and cognitive screening integrated into routine epilepsy care is sources of funding. In terms of billing practices, only half of programs indicated specific billing procedures. It is likely that the neurologists completing the survey mostly represent those with specific billing practices. Many programs task psychology postdoctoral fellows with screening, and there may be barriers to billing for these providers as they are still in training. A little over a third of programs endorsed institutional support as a way to fund screening, and very few indicated grant support. Therefore, one of the significant challenges to enhancement and sustainability of screening in routine epilepsy care may be funding, and efforts to increase resources in this area are important. Efforts may include public policy changes at the national and state levels, budget line items, and increased education and awareness of billing codes and their effective use for behavioral health professionals.

The results of this survey indicate that behavioral health screening is incorporated into routine epilepsy care in a number of centers, suggesting forward momentum in screening practices. Development of more standardized assessment and screening guidelines may be the logical next step and be beneficial for patients, families, and epilepsy providers.

A three-tiered model of behavioral health screening/assessment has been proposed [32,33]. In this model, step one includes screening all patients for suicidal ideation, emotional and behavioral concerns, self-management, social concerns, and medication adherence. If no concerns are identified, no intervention is recommended, and the patient should be rescreened *annually*. If concerns are identified (Tier 2), then a more thorough diagnostic assessment tool should be used and referral to a behavioral health provider should be made, if indicated. Follow-up at subsequent epilepsy visits is warranted. Patients in Tier 3 are those with known mental, neurocognitive, or behavioral health diagnoses. Providers should screen these patients for difficulties with self-management and adherence at each epilepsy visit, assess whether appropriate services and support are being provided for previously identified behavioral health and cognitive needs, and make any newly indicated referrals. Notably, there is a precedent for the integration of behavioral health during routine epilepsy care in a multidisciplinary setting [25]. Sole reliance on a consultation or referral model may result in failure to identify those children with subclinical symptoms or prevent symptoms from worsening. Further, providing behavioral healthcare as a component of routine epilepsy care may also reduce stigma associated with behavioral healthcare. Whether behavioral healthcare is provided in the epilepsy clinic or in another setting, the epilepsy provider is encouraged to reinforce the importance of follow through with behavioral health treatment at each epilepsy visit. Future research may include validating the usefulness of this three-tiered model empirically in order to assist with the development of more formal best practice recommendations.

The current survey data are not without limitation. Specifically, a relatively small sample of professionals completed this survey. However, according to AES records, approximately 45% of members have indicated a practice area. Of that group, 70 individuals have indicated “psychology/neuropsychology” or “psychiatry/neuropsychiatry”. Therefore, it is possible that approximately 36% of centers, who have behavioral health professionals integrated on the team, responded to the survey, a modest but not unreasonable response rate to electronic surveys. There are currently 137 specialized epilepsy centers in the United States who provide pediatric care, and our sample of 24 represents 7.6% of them. Notably, our survey was sent through AES, and only AES members would have seen the announcement [24]. In addition, there is likely sampling bias in that centers with behavioral health professionals self-selected to participate because they recognize the importance of these health professionals as part of the comprehensive epilepsy healthcare team. Future studies may consider increasing the sample size to include a larger cross section of centers, including the ones that do not have behavioral health professionals on site to address barriers.

5. Conclusions

In conclusion, our results suggest that behavioral health screening is routinely incorporated in a number of epilepsy centers responding to a survey disseminated through the largest epilepsy professional society in the US. However, there is significant variability in the assessment measures/methods utilized, who is administering them, and the purposes of the assessment (i.e., screening versus aiding in diagnosis). Standardization of clinical behavioral health assessment would be beneficial and requires an updated guideline and educational platforms to inform healthcare professionals about standardized behavioral health assessment tools, practice, and resources [1,2]. The 3-tiered model of behavioral health screening may function as a framework for developing such guidelines [18,19]. As more epilepsy clinics and centers incorporate behavioral health screening into their routine practice, and if these procedures are standardized across sites, then it will provide clinical data for review and analyses, likely leading to improved clinical management of epilepsy and its comorbidities (e.g., current efforts of the PERC for treatment of infantile spasms). Such efforts align with exactly what the Epilepsy Learning Healthcare System is striving to achieve — collaborative efforts in the evaluation of practice and patient outcomes to inform changes that enhance epilepsy education and care [22], and subsequently, patient health outcomes improve.

Declaration of competing interest

The authors report no conflicts of interest.

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