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Brief Communication

Parental perspectives on provider adherence to AAN epilepsy quality measures in rural and urban tertiary care centers☆

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ABSTRACT

Several American Academy of Neurology (AAN) epilepsy practice guidelines recommend conversations that neurologists should have with patients and their parents. We sought to determine whether parents of pediatric patients with epilepsy had knowledge of epilepsy quality measures (EQMs) and whether they recalled having discussions with their child's neurologist about each of the EQM. Surveys were distributed to parents at five clinic sites associated with epilepsy centers in Washington, DC and Charlottesville, Virginia. Key questions on the parent survey included whether neurologists had discussed, or parents had knowledge of, EQM topics which included medication side effects, safety, reproductive health, transition to adult care, learning and attention problems, bone health, sudden unexpected death in epilepsy (SUDEP), and risk of epilepsy-related death. No data were collected from the neurologist or the medical record about EQM discussions. Among 233 completed surveys, parental knowledge and neurologist discussion of EQM were highly correlated ($p < .00001$). Epilepsy quality measures most discussed with high parental knowledge were medication side effects, safety, learning and attention problems, and bone health. Sudden unexpected death in epilepsy was least discussed and known. We found consistent care practices in adherence to EQM across settings from urban to rural communities, with patients of all ages and epilepsy severities and staffed by neurologists with various levels of epilepsy expertise. Despite reported high rates of adherence on several measures, we identified opportunities for improvement. Querying and counseling about EQM should be an ongoing conversation which evolves with the child's age and epilepsy-associated risks.

1. Introduction

Practice guidelines for pediatric epilepsy developed by the American Academy of Neurology (AAN) include discussing the risks of epilepsy, treatments, outcomes, and the transition to adult care with patients and families [1–3]. Previous reports from medical record abstraction and neurologist surveys demonstrated the prevalence of adherence to the epilepsy quality measures (EQMs); however, these reports are from the provider's perspective [4–6]. We surveyed parents to determine their knowledge of selected EQM topics and their recall of discussing EQM items with their neurologist with the purpose of understanding whether risk information discussed by the neurologist was retained by the parent.

2. Material and methods

Between August 2016 and January 2018, paper surveys [Supplemental material] were given to a convenience sample of 245 parents/legal guardians (hereafter referred to as parents) of children with epilepsy at five clinic sites associated with Level 4 epilepsy centers at Children's National Health System and the University of Virginia after Institutional Review Board (IRB) approval, and oral informed consent was obtained. These institutions care for patients in urban, suburban, and rural communities. The sites (Washington DC, Rockville MD, Fairfax VA, Charlottesville VA, and Southwest VA) are staffed with general neurologists and epileptologists. Southwest VA is a field clinic, not limited to children (i.e., there is no transition to adult care), and operates in three towns allowing tertiary epilepsy care to occur in rural communities. Eligibility criteria for parents included English speaking and having a child at least

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six months of age with a confirmed diagnosis of epilepsy. There was no upper age limit for the child. There was also no minimum number of prior clinic visits required, although all children had been previously seen by a neurologist at the enrolling site at least once and most children were longer term follow-up patients. There were no data collected from the neurologists or from the child's medical record. Surveys were given to the parents while they were waiting for the doctor, and they were collected at the end of the visit by the study coordinator. Twelve incomplete surveys (4.9%) were excluded. Key questions on the parent survey included whether neurologists had ever discussed eight EQMs with the parents and whether parents had knowledge about these measures (answer choices: yes, no, don't know). Epilepsy quality measure topics included antiepileptic drugs' (AEDs) side effects, injury prevention, reproductive health and transition to adult care in children age 12 or older, learning and attention problems, vitamins to improve bone health, epilepsy-related death in general, and sudden unexpected death in epilepsy (SUDEP). Missing and "don't know" responses for both knowledge of a topic and whether the neurologist discussed it were recoded as a "No" since we were interested in whether knowledge was obtained. Ten children under age three years were excluded from analyses of neuropsychiatric comorbidities. Fourteen children with missing age were excluded from age-dependent analyses. Data analyses conducted in SAS version 9.4 included logistic regression for whether neurologist discussion about each topic varied separately by patient characteristics (seizure type, seizure duration, current AEDs, developmental or learning disability, intellectual disability, attention-deficit/hyperactivity disorder (ADHD), autism, anxiety, and depression), mother's education, and family income after adjusting for patient age and clinic site. Correlation coefficients measured strength of associations between neurologist discussion and parental knowledge about each EQM. Significance tests were 2-sided, and statistical significance was achieved when the p-value was less than .05. The study was approved by Institutional Review Boards at Children's National Health System and the University of Virginia. A study coordinator obtained oral informed consent from each parent prior to their completion of the survey.

3. Results

Of the 233 parent surveys included in the analyses, 64 were from Washington, 49 from Rockville, 43 from Fairfax, 15 from Charlottesville, and 62 from Southwest VA. Mean age of the children was 12.0 years (95% confidence interval (CI): 11.3–12.7) and 123 (53%) were at least 12 years of age. Primary seizure types based on parental descriptions were mostly generalized motor ($n = 178$; 76.4%) and were missing for 10 (4.3%) children. The current number of AEDs reported was zero in 8 (3.4%) children, 1 drug in 99 (42.5%) children, 2 drugs in 51 (21.9%) children, more than 2 drugs in 49 (21.0%) children, and missing in 26 (11.2%) children. Prevalence of comorbidities in all children included 148 (63.5%) with developmental or learning disability and 58 (24.9%) with intellectual disability. Among 223 children at least three years of age, parents reported that 62 (27.8%) had ADHD, 28 (12.6%) had autism, 68 (30.5%) had anxiety, and 19 (8.5%) had depression. Mother's education included 83 (35.6%) with not more than a high school diploma and 102 (43.8%) with at least a college degree. The household income was less than $25,000 in 40 (17.2%) families and at least $100,000 in 80 (34.3%) families; 14 (6%) did not answer the question. There were no significant differences in the study populations across the five sites for any of the demographic or clinical characteristics including child's age, epilepsy characteristics, developmental and neuropsychiatric comorbidities, mother's education, and family income.

According to the parents, EQMs most discussed by the neurologists with a corresponding high presence of parental knowledge were medication side effects (90.5% and 84.5%, respectively), safety to avoid injuries (85.0% and 84.1%), learning and attention problems (73.9% and 76.9%), and vitamins to improve bone health (61.8% and 64.4%) (Table 1). A minority reported that neurologists discussed or there was parental knowledge about reproductive health issues (36.6% and 41.4%) or transition to adult care (41.5% and 37.2%) for children at least 12 years old. The topic discussed by neurologists and known about by parents the least was SUDEP (29.2% and 31.3%, respectively), yet a majority of parents reported that they had knowledge about and the neurologist discussed with them the risk of death (71.3% and 56.7%, respectively). While there were moderate to strong correlations ($p < .001$) between parental knowledge and neurologist discussion of the various EQMs (Table 1), discrepancies occurred. A small number of parents reported that a discussion had occurred about an EQM topic, even though they also reported not knowing about the topic (3.9–7.7%). Conversely, some parents said they knew about the topic despite it not having been discussed by the neurologist (1.7–18.5%).

There were no significant differences across sites in parental reports of discussion of any of the EQM based on the epilepsy characteristics, comorbidities, child's age, mother's education, or household income. Although Rockville and Fairfax neurologists tended to discuss EQM with the lowest frequencies, there was a site effect ($p = .03$) only for whether neurologists discussed the need for vitamins to improve bone health with a higher rate at Washington (51 [79.7%]), compared with 7–38 [44.2%–61.3%] at the other sites; Fig. 1.

Among 223 (95.7%) parents that responded how they wanted to receive information about epilepsy-associated risks, 214 (96.0%) said they wanted the information during a doctor visit and 9 (4.0%) wanted the information by email, text, or mail from the child's doctor.

4. Discussion

This report on adherence to EQM that involves neurologist–parent discussions and parental knowledge of the measures is the first from

Table 1
Neurologist discussion and parental knowledge of epilepsy quality measures.

EQM	Neurologist discussed		Neurologist did not discuss		Correlation coefficient[a]
	Parental knowledge	No parental knowledge	Parental knowledge	No parental knowledge	
	No. (%)	No. (%)	No. (%)	No. (%)	
Medication side effects	193 (82.8)	18 (7.7)	4 (1.7)	18 (7.7)	.593
Safety to avoid injury	185 (79.4)	13 (5.6)	11 (4.7)	24 (10.3)	.606
Learning/attention problems	156 (67.0)	16 (6.9)	23 (9.9)	38 (16.3)	.552
Need for vitamins	130 (55.8)	14 (6.0)	20 (8.6)	69 (29.6)	.688
Risks of death	123 (52.8)	9 (3.9)	43 (18.5)	58 (24.9)	.554
SUDEP	56 (24.0)	12 (5.2)	17 (7.3)	148 (63.5)	.706
Reproductive health[b]	39 (31.7)	6 (4.9)	12 (9.7)	66 (53.7)	.697
Transition to adult care[b,c]	35 (37.2)	4 (4.3)	0	55 (58.5)	.915

EQMs = epilepsy quality measures.
SUDEP = sudden unexpected death in epilepsy.
[a] All correlations are significant at $p < .001$.
[b] In children at least 12 years of age.
[c] Excludes 29 from Southwest, VA where there is no transition of care.

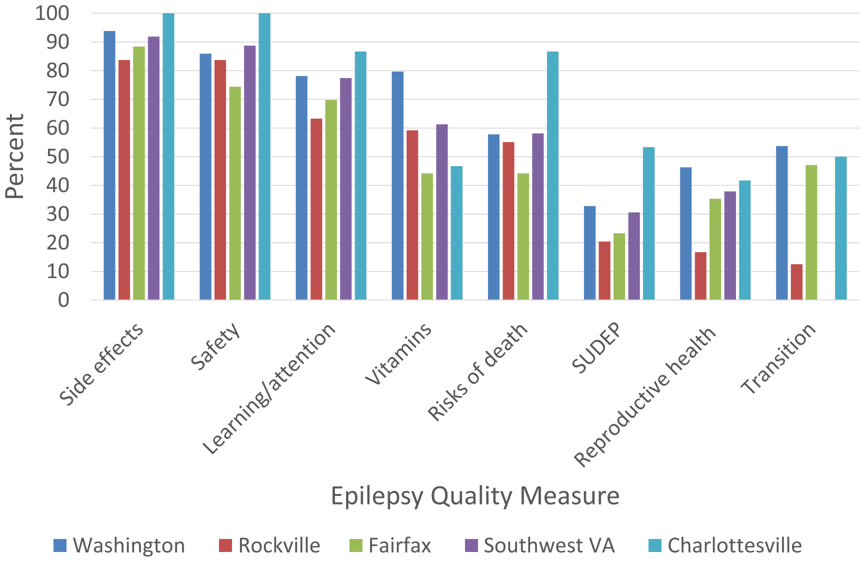

Fig. 1. Proportion of neurologists that talked about the epilepsy quality measures at each site. No bar is included for Southwest, VA for transition to adult care because patients do not transition at this site.

the family perspective. We found that parents reported consistent care practices in adherence to EQM discussions across five settings from urban to rural communities, which had patients of all ages and epilepsy severities and were staffed by neurologists with various levels of epilepsy expertise.

The EQMs with the most neurologist discussion and parental knowledge in our study were AED side effects and safety issues. Similar results were found in a previous study of adherence to EQM using abstractions of medical records from a pediatric epilepsy cohort, where 84.2% indicated a discussion about side effects and 55% documented a discussion about safety [6]. These findings and ours are higher than those reported by Pourdeyhimi et al. from a review of 200 adult and pediatric patients with epilepsy records [5]. In that study, 68.3% documented a discussion about AED side effects and, 39.2% documented a discussion about safety.

In our study, conversations about learning and attention issues, which were prevalent in our population, also frequently occurred, although comorbidities that appear later in childhood may not always be discussed in the youngest patient populations. We did not survey whether discussion of other specific developmental and psychiatric comorbidities such as autism, depression, and anxiety disorders occurred.

There may be reasons why the parent reports showed that some topics were not uniformly discussed across the five epilepsy sites or within the patient populations. The higher frequency of discussing bone health in Washington DC likely reflects an ongoing targeted bone health initiative at that epilepsy center. For reproductive health, there was likely more discussion with girls; however, a limitation of our study was not asking for patient gender in order to stratify the analysis. Assuming half the patients are female, the discussion occurred in approximately 80% of the relevant population. Current recommendations are to introduce the concept of transition to adult care at age 12 years even though many centers do not transfer care until age 18–21 years [3,7]. These age recommendations may not have entered fully into common practice.

Discussions of death and SUDEP were discrepant, and 19% of parents had knowledge of death despite not recalling discussing it with their child's neurologist. Conversations about death are difficult. The reason why SUDEP may not be discussed often is that neurologists may start with more preventable risks (e.g., water safety) to establish rapport with families before talking specifically about SUDEP, which has no proven preventative measures. Despite neurologists' concerns about causing anxiety, parents have consistently reported that they want to learn about SUDEP from the child's doctor [8,9]. Higher parental knowledge about mortality risk than was discussed by neurologists indicates that parents obtain crucial epilepsy information from other sources. A previous study found that the main source of epilepsy information for patients and caregivers was the internet [8]. Thus, knowing that 96% of parents in our study wanted to learn about epilepsy risks directly from their child's doctor, neurologists should feel encouraged to address topics directly with parents to reduce misinformation obtained from the internet and to assure that the risk information conveyed is thoroughly understood.

There were several limitations with our study. As noted previously, we did not ask parents about the gender of the child with epilepsy. Surveys were anonymous and missing information could not be subsequently obtained. We did not collect information about the frequency or severity of the child's seizures or the duration of epilepsy which may influence if, when, and how often the neurologist choses to discuss the various EQM topics with the parents. We also did not determine the number of previous epilepsy clinic visits which may influence whether the EQM had ever been discussed or whether the knowledge about an EQM was retained, as comprehensive discussions of all topics likely occur over several visits, and each one may not be discussed at every follow-up visit. Furthermore, the survey was cross-sectional and reporting of discussions that occurred in the more distant past between neurologist and parent, or those topics that were discussed less frequently than others, may suffer from parental recall. We did not determine the occurrence or frequency of discussions about risks from the neurologist's perspective, and in fact, we expected adherence to the guidelines by most of them with the understanding that discussions of all epilepsy-related risks may not occur at a single point in time or at every visit. Nonetheless, the objective of our study was to understand whether parents remembered the neurologist discussing the risks of epilepsy at any time, which may influence the ongoing management of their child's disorder outside the clinical setting.

4.1. Conclusions

Despite reported high rates of adherence on several EQM measures, this survey from the parent's perspective suggests that neurologists may not communicate the most profound epilepsy risks, such as mortality, including SUDEP. In light of the recent findings by Keller et al. that indicate the incidence of SUDEP is more common in the pediatric population than previously considered, adherence to discussion of this topic with parents and adolescent patients is even more important [10]. Neurologists should consider including the SUDEP acronym during their discussions because it is memorable and allows families to directly search for the many SUDEP resources available on the internet. Finally, querying and counseling about EQM should be an ongoing conversation which evolves with the child's age and their epilepsy-associated risks.

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Appendix A. Supplementary data

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