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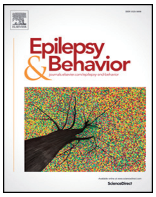

Brief Communication

Quality of life improves with integrated behavioral health services in pediatric new-onset epilepsy

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ABSTRACT

The current study compared differences in health-related quality of life (HRQOL) between youth with new-onset epilepsy with and without elevated psychological symptoms at time of epilepsy diagnosis within an integrated behavioral health and epilepsy service. Patients received both behavioral health and epilepsy care during clinic visits. A retrospective chart review was conducted between July 2011 and December 2015. Caregivers completed the Behavior Assessment System for Children-2: Parent Rating Scale (BASC-2: PRS) to assess psychological symptoms at the diagnostic visit, along with completing the Pediatric Quality of Life Inventory (PedsQL™ 4.0) at the diagnostic visit and each subsequent epilepsy clinic visit during the first year of treatment. Latent growth curve modeling was used to identify HRQOL changes over the first year of treatment. Health-related quality of life was significantly lower for youth with elevated psychological symptoms at diagnosis and over the first year of treatment compared with those without psychological symptoms. For those with elevated internalizing, inattention, withdrawal, and atypical symptoms at diagnosis, greater HRQOL improvements were detected over the first year of treatment compared with those without elevated psychological symptoms at the diagnostic visit. Within integrated behavioral health and epilepsy routine care, targeted psychological interventions can improve HRQOL over the first year of treatment, particularly for those with premorbid psychological symptoms.

1. Introduction

Disruptive behavioral disorders, learning disorders, and internalizing disorders (i.e., depression, anxiety) are common in pediatric epilepsy [1–3]. Although majority of studies have focused on the cooccurrence of psychological symptoms during the course of epilepsy, several studies have documented increased risk for symptoms even prior to epilepsy onset [4,5]. Further, premorbid psychological symptoms are related to poorer epilepsy prognosis [6]. Thus, identification of psychological functioning prior to epilepsy treatment initiation may provide a key insight into which patients are at highest risk for complications and compromised health-related quality of life (HRQOL) during the first year of epilepsy treatment [5].

Despite the high prevalence of psychological symptoms, few pediatric comprehensive epilepsy centers have standardized routine screening for common psychological comorbidities that impact HRQOL in youth with epilepsy (YWE). Health-related quality of life is a critical patient-reported outcome [7,8] capturing the impact of disease and treatments on the daily functioning of youth. Optimizing seizure control and HRQOL is imperative. Integrated behavioral health and epilepsy care has significant potential to mitigate psychological comorbidities and enhance HRQOL [9,10] by allowing for proactive and targeted psychological interventions early in the disease process.

The current study compared differences in HRQOL between youth with new-onset epilepsy with and without elevated psychological symptoms at time of epilepsy diagnosis (i.e., baseline) in the context of an integrated behavioral health and epilepsy clinic. Given the model of proactive interdisciplinary care, we hypothesized that youth with baseline psychological symptoms would have greater improvements in HRQOL over the first year of epilepsy treatment compared with those without baseline psychological symptoms.

2. Methods

2.1. Standard protocol, approvals, registrations, and patient consents

The Institutional Review Board approved the retrospective medical chart data extraction for this study.

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2.2. Pediatric New Onset Seizure Clinic

Participants included children and adolescents with new-onset epilepsy and their caregivers seen between July 2011 and December 2015 in our New Onset Seizure (NOS) Clinic. The NOS Clinic treats a homogenous cohort of youth 2–18 years of age who are typically developing without significant medical (e.g., diabetes), psychiatric (e.g., bipolar), or developmental (e.g., autism) needs as reported by caregivers prior to initial diagnostic visit. However, patients with Attention-Deficit Hyperactivity Disorder (ADHD), mild developmental delays, or undiagnosed mood disorders are seen in the clinic. Patients with undiagnosed medical and psychological comorbidities that are uncovered at diagnosis or over the course of treatment continue to receive care in the NOS Clinic. No additional exclusion criteria were considered for the purpose of the current study. The NOS Clinic model is an integrated behavioral health and epilepsy clinic in which pediatric clinical psychologists specialized in epilepsy provide universal routine screening and treatment to address the psychological needs of YWE (See Guilfoyle et al. [11] for a comprehensive overview of the clinic). During the initial diagnostic visit with the epileptologist (i.e., baseline), caregivers complete measures of their child's psychological functioning and HRQOL. Caregivers complete HRQOL measures at all subsequent clinic visits, which typically occur every three months. Patients see the psychologist, on average, twice per year for routine behavioral health consultations. However, if a higher level of care is warranted, the team psychologists were available to provide more intensive outpatient behavioral health services. During these visits, the psychologist conducts brief assessments, reviews completed behavioral/emotional and HRQOL screening questionnaires, and provides evidence-based treatment strategies to remediate psychological symptoms and improve HRQOL.

2.3. Measures

2.3.1. Behavior Assessment System for Children-2: Parent Rating Scale, (BASC-2: PRS) [12]

The BASC-2: PRS is a 134- to 160-item parent-report measure of behavior and personality in youth across three age groups: preschool (2–5 years), child (6–11 years), or adolescent (12–21 years). Depending on the age group, the BASC-2: PRS yields 4 to 5 composite scales (e.g., Internalizing Problems, Externalizing Problems, Behavioral Symptoms Index, Atypicality, and Adaptive Skills). The measure yields T-scores, with scores between 60 and 69 being “at-risk” and T-scores ≥70 being clinical elevations representing a high level of maladjustment. The BASC-2: PRS has demonstrated reliability and validity in pediatric populations with epilepsy [13–15], and internal reliability ranges from 0.58 to 0.89. For the current study, Internalizing, Externalizing, and Behavioral Symptoms Index (i.e., inattention, withdrawal, atypicality) composite scores were used. For each composite score, we defined two groups based on T-score cutoffs: normative scores (i.e., T-scores <60) versus at-risk/clinically elevated scores (i.e., T-scores >60).

2.3.2. Pediatric Quality of Life Inventory (PedsQL™ 4.0) [16]

The PedsQL™ 4.0 Parent Report is a 23-item generic HRQOL measure for caregivers of children between 2 and 18 years of age. The PedsQL™ 4.0 assesses physical, emotional, social, and school functioning. The PedsQL™ 4.0 is valid and reliable across versions (rs = 0.89–0.90) [7, 16]. Scores range from 0 to 100, with higher scores representing better quality of life. The Total Score was used in the current study.

2.4. Medical chart review

Two trained clinical research coordinators extracted demographic and clinical data through electronic medical chart review. Clinical data included the following: antiepileptic drug and side effects, epilepsy classification, baseline age, presence/absence of seizures in the past month, baseline psychological functioning (BASC-2: PRS), and HRQOL (PedsQL™ Parent Report).

2.5. Data analytic plan

To determine the type of change in HRQOL over the five time points, we first conducted an unconditional latent growth model. We assessed goodness of fit based on empirically supported indices [17]: (1) root mean square error of approximation (RMSEA) values less than 0.05 and (2) comparative fit index (CFI) values greater than 0.95. Once we determined whether the change over time was best modeled as linear or nonlinear, we fit a conditional latent growth curve model where baseline psychological symptom grouping (i.e., normative vs. at-risk/clinically elevated) was the predictor of both initial HRQOL (i.e., intercept) and HRQOL change over the first year of epilepsy treatment (i.e., slope). This conditional model was controlled for antiepileptic drug side effects, baseline child age, and the presence/absence of seizures in the past month. All analyses were conducted in Mplus v.8 with robust maximum likelihood estimation to account for missing data [18].

3. Results

3.1. Sociodemographic and medical characteristics

At diagnosis, the sample included 379 YWE ranging in age from 2 to 18 years ($M_{age} = 8.9$ years, SD = 4.7) and their caregivers, with gender equally divided ($F_{ave} = 50.7\%$) and a majority Caucasian (83.6%) with private insurance (60.4%). A majority of the sample had a diagnosis of generalized epilepsy (41.7%) while the remaining sample had focal epilepsy (34.6%), unclassified epilepsy (22.7%), or a single seizure (1.1%) Most were prescribed levetiracetam (33.5%), valproic acid (19.0%), ethosuximide (18.7%), carbamazepine (14.8%), or other (<5.0%). Approximately half of the sample had seizures within the past month of diagnosis (50.6%).

3.2. Latent growth curve modeling

A linear unconditional latent growth model for overall HRQOL was a good fit to the data (RMSEA = 0.05; CFI = 0.95), suggesting that HRQOL change across the first year of treatment was linear. For the overall sample, HRQOL was initially high (mean intercept = 80.95) [19], although significant individual variability was detected in these initial values ($p < 0.001$). Additionally, HRQOL remained fairly stable over time (slope = −0.30, $p = 0.50$), with significant individual variability also found in the slope of HRQOL trajectories, $p = 0.01$.

For the conditional models, we examined three different aspects of psychological functioning (i.e., BASC-2 Internalizing, Externalizing, Behavioral Symptoms Index), after controlling for covariates. All three conditional models were an adequate fit to the data (RMSEA = 0.04–0.05; CFI = 0.94–0.91).

Youth with at-risk/clinical internalizing elevations (23.9%) had significantly lower initial HRQOL than those without internalizing elevations ($b = -12.91$, $p < 0.001$). Additionally, youth with internalizing elevations had a steeper slope than those without internalizing elevations ($b = 2.79$, $p < 0.01$), suggesting that youth with internalizing elevations had greater improvements in overall HRQOL compared with those without (Fig. 1a).

Youth with at-risk/clinical externalizing elevations (23.3%) had significantly lower initial HRQOL than those without externalizing elevations ($b = -9.98$; $p < 0.001$). However, HRQOL rates of change did not differ ($b = 1.66$, $p < 0.05$) for the externalizing group over time, indicating that HRQOL remained stable for this group over the first year of treatment (Fig. 1b).

Finally, youth with at-risk/clinical Behavioral Symptom Index elevations (i.e., atypical, inattention, withdrawal symptoms; 28.8%) had

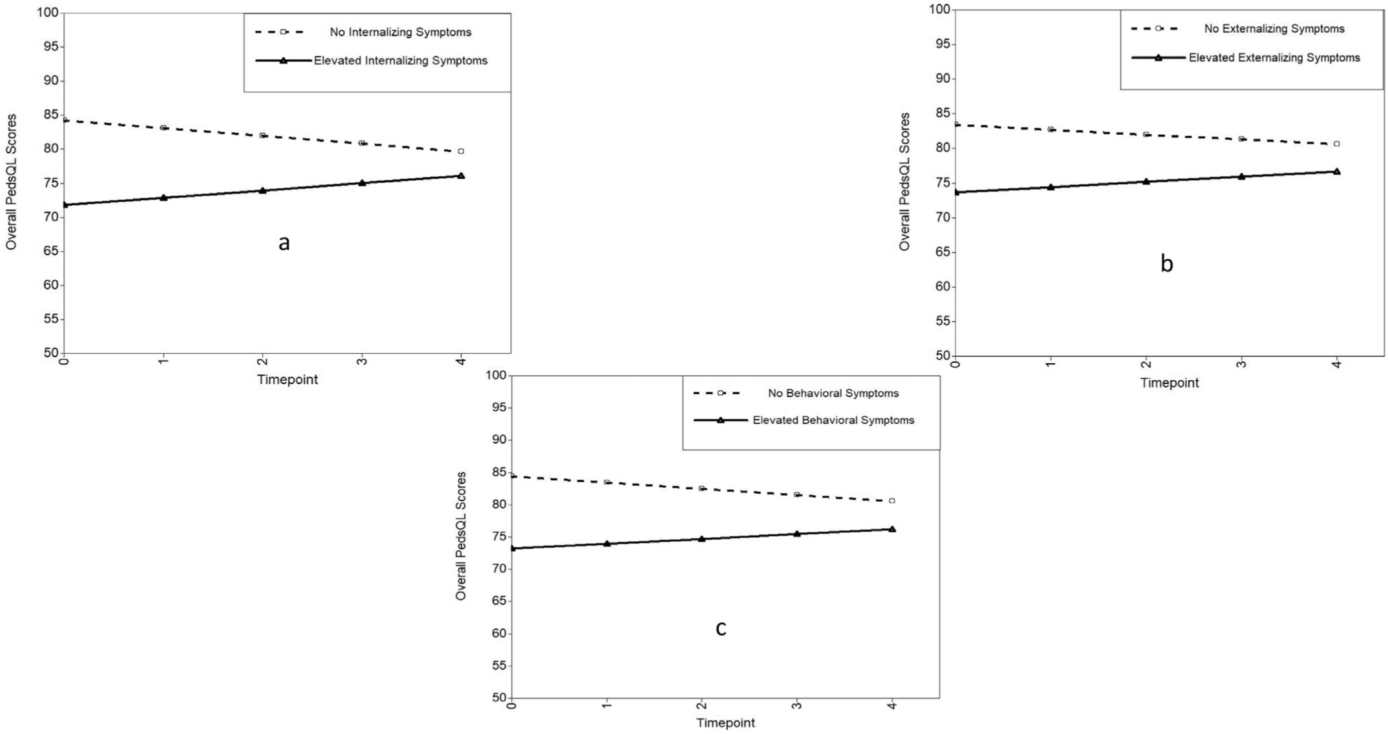

Fig. 1. Quality of Life Trajectories in Pediatric New-Onset Epilepsy.

significantly lower initial HRQOL scores compared with those without these elevations ($b = -11.98$, $p < 0.001$). Further, youth with behavioral symptom elevations had a steeper slope than those without ($b = 2.52$, $p = 0.05$), indicating that those with behavioral symptom elevations had greater improvements in overall HRQOL compared with those without these elevations (Fig. 1c).

4. Discussion

Our overarching goal was to examine changes in HRQOL, a critical patient-reported outcome, between YWE with and without specific types of psychological symptoms at diagnosis within an integrated behavioral health and epilepsy clinic within the first year of treatment. As hypothesized, YWE with elevated internalizing, atypical, inattentive, and withdrawal symptoms had greater improvements in HRQOL across the first year compared with those without psychological symptoms at diagnosis. Those without psychological symptoms maintained healthy HRQOL over time. In contrast, YWE experiencing externalizing symptoms did not exhibit improved HRQOL over time. The lack of findings for externalizing symptoms could be attributable to several factors: 1) the transient nature of externalizing symptoms compared with internalizing symptoms, 2) misattribution of externalizing behavior to antiepileptic drug (AED) behavioral side effects, and/or 3) parental acquiescence to externalizing behavior due to fear of triggering seizures. Overall, integrating behavioral health services into routine epilepsy care can significantly improve HRQOL, particularly for those YWE who have elevated psychological symptoms prior to epilepsy treatment initiation. Obtaining behavioral health screening at diagnosis, prior to onset of AED, allows for early detection of psychological symptoms, how they may impact epilepsy course of treatment, and whether parental practices need to be modified based on the course of behavior during epilepsy treatment.

Interestingly, compared with published norms of YWE for HRQOL, our sample demonstrated similar scores at baseline. However, when subgroups of patients were examined separately based on psychological symptom elevation (i.e., normative versus at-risk/clinically elevated), we found that YWE with elevated psychological symptoms had significantly lower baseline HRQOL. We found a similar pattern in our epilepsy clinic related to the assessment of depressive symptoms [9], suggesting that early identification of psychological symptoms is critical for improving outcomes.

Because of behavioral health screening for psychological symptoms at diagnosis, determining the level of need from the service allows for a personalized medicine approach. While an integrated behavioral health and epilepsy clinic is ideal for routine monitoring and treatment, it is not common across epilepsy centers. However, we encourage comprehensive epilepsy centers to engage behavioral health providers (e.g., psychologists, social workers) to aid in early detection of psychological symptoms given its long-term impact on HRQOL. This is especially important for the subset of youth with intractable seizures who are at great risk for AED polytherapy and exposure to more AED side effects, a predictor of HRQOL [20]. However, improving HRQOL is feasible through proactive screening and intervention. If providers are not able to integrate behavioral health screening into routine care, tracking HRQOL will allow for early referral to local community-based behavioral health providers.

Limitations to the study include the use of the BASC-2 at a single time point (e.g., diagnosis) to assess psychological symptoms. Further, both the BASC-2 and PedsQL 4.0 are generic measures that may not best capture the salient aspects of epilepsy symptoms and treatment. The PedsQL Epilepsy Module, an epilepsy-specific measure of HRQOL, has been developed and will be an important HRQOL outcome for future pediatric epilepsy research. And last, given that socioeconomic status predicts HRQOL [21], further investigation of its impact on HRQOL is warranted. The strengths of the study include a large representative clinical sample, the use of reliable and widely used measures, and the longitudinal design. Overall, our study demonstrates the benefits of screening and addressing psychological symptoms at diagnosis via our integrated behavioral medicine and epilepsy clinic. Addressing psychological symptoms proactively has the ability to positively influence HRQOL over the course of the first year of epilepsy treatment, regardless of seizure control.

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Disclosures of conflicts of interest

None of the authors has any conflict of interest to disclose.

Ethical publication statement

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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