

Berg AT, Smith, SN, Frobish D, Beckerman B, Levy SR, Testa FM, Shinnar S.
Diagnosed epilepsy: influences of etiology, syndrome, and seizure control.
Pediatrics 2004;114:645-650.

Objectives. The outcomes of childhood-onset epilepsy are highly varied and have several potential determinants. We examined the independent effects of syndrome type, seizure control, and etiology over time on adaptive behavior as measured by the Vineland Scales of Adaptive Behavior.

Methods. As part of a prospective community-based study of newly diagnosed epilepsy, parents of children who were younger than 3 years at the time of initial onset of epilepsy completed the Vineland Adaptive Behavior Scales screener version at entry into the study and once a year thereafter for up to 3 years. Longitudinal analyses were performed on the composite score as the primary outcome and on the 4 domain scores (communication, socialization, motor, and daily living) as confirmatory/secondary outcomes to determine the effects of syndrome (epileptic encephalopathy or other), seizure control (intractable or not), and etiology (symptomatic or not) on adaptive behavior at the time of initial diagnosis and over time.

Results. A total of 613 children were enrolled in the study, and 191 (31%) of these children met the age criterion for this analysis. Of these, 172 (90%) had adequate follow-up and had completed baseline and at least 1 subsequent Vineland assessment. Overall, Vineland scores (composite and individual domains) were somewhat below average at baseline (initial diagnosis). All declined significantly over time. All of the effects at baseline, however, were limited to children with epileptic encephalopathies and symptomatic etiology. Substantial declines over time occurred in these children, and there was an independent effect of intractable seizures as well. In children with none of these factors (~75% of the study group), baseline scores were consistent with average performance for the test norms and there was no evidence of any decline over time.

Conclusions. Children with an underlying symptomatic etiology or a syndrome that can be characterized as 1 of the epileptic encephalopathies demonstrate impaired adaptive behavior at the time of initial diagnosis and experience additional declines in assessments of age-adjusted performance over time. Our results suggest that future seizure outcome is not strongly reflected in adaptive behavior at initial diagnosis but that it takes its toll on the child over time. Understanding how each of these factors affects development and how they interact with each other is the next step in designing effective interventions for lessening the impact of these disorders on the child. In the majority of children with onset of epilepsy during infancy or early childhood, adaptive behavior is within the normal range and does not show any evidence of declining over time. Although this is encouraging, it does not contradict other studies that have demonstrated behavioral and relatively subtle cognitive difficulties in school-aged children with epilepsy. Long-term follow-up in this cohort will permit us to examine the predictive value of the Vineland for later behavioral and cognitive difficulties in this group that, so far, seems to be doing well.