



# Pediatric Epilepsy: The Importance of Neuropsychological Consultation in Collaborative Care Teams and Identifying Areas for Improvement

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### Abstract

Pediatric Epilepsy care is primarily managed by a neurologist. Children with epilepsy often live life with minimal complications. However, many other children have extensive complications associated with epilepsy. These complications at times extend beyond the scope of practice of a neurologist, and are best served with specialized care. A coordinated care team model can achieve this goal, but are usually available only through major medical centers. The need for collaborative care extends far beyond the scope of what a major medical center can provide due to patient volume, needs in rural areas, and ancillary medical needs. Although all non-neurology professionals with a subspecialty in epilepsy are important in the overall care of children with epilepsy, neuropsychology in the collaborative relationship with neurology will be the primary focus of this article. Identifying specific roles and providing recommendations for improved care will be discussed.

### Keywords

Pediatric epilepsy; Collaborative care; Neuropsychology; Neurocognitive sequela

## Background

Pediatric Epilepsy care is typically managed by a neurologist. Many children with epilepsy live life with minimal complications. Their seizures are well controlled by medication and are without neurocognitive sequela or emotional problems. At the most, these children have a safety plan outlined at school in the form of a seizure protocol with little need for more extensive collaborative care. However, many other children have more extensive complications associated with their epilepsy that extend beyond the bandwidth of a neurologist, in part due to the shortage of neurologists in the United States, time pressures faced by physicians, and in part related to the multifaceted complications experienced by a subset of youth with epilepsy [1]. The need for management of these complications is exemplary. In brief, children with epilepsy have high rates of comorbid complications that include: Attention Deficit/Hyperactivity Disorder

(8-77% depending on study), high rates of intellectual disability, learning disabilities (up to 25%), autism (5%), depression (8-33%), anxiety (15-50%) and once children reach adulthood, they are 3.5 to 5.8 times more likely to commit suicide, have more difficulty holding a job, live independently, and have a partner [2-6].

Value-based payment will determine reimbursement based on outcomes and quality measures. Team-based care can facilitate these desired higher quality outcomes [1]. Many children with epilepsy obtain their neurological care at major medical centers where there is more access to team-based care and may receive complementary care from neuropsychology, special education, genetics, social work, nursing, and rehabilitation specialists (behavioral health, occupational, physical, and speech and language therapy). There are also additional medical team members important to the collaborative process that will not be discussed due to the scope of this article (i.e. dietetics, psychiatry, genetics, endocrinology, metabolic, neuro-oncology, psychiatry, etc.). The need for collaborative care extends far beyond the scope of what major medical centers can provide due to volume, needs in rural areas, and ancillary service needs. Collaborative care involving the aforementioned team members warrants acknowledgement and discussion. However, given the scope of this article, discussion of what neuropsychology's value adds in the collaborative care within pediatric epilepsy and neurology will be the primary focus.

## Role of Neuropsychology in Pediatric Epilepsy

Neurologists provide the essential role in the process of diagnostic evaluation, treatment, monitoring, and care planning in pediatric epilepsy. Given neuropsychology's advanced and specific training in brain anatomy, anatomical function, and the brain-cognition-behavior relationship, the profession is in a unique position to offer specialized services including neuropsychological evaluation, consultation, treatment planning and family counseling/psychoeducation, collaborating with educators, and training other professionals.

Within the collaborative relationship with neurology, the neuropsychologist can consult on the acute and long-term neurocognitive and emotional/behavioral sequelae of various seizure types, discuss emotional/behavioral functioning, medication side effects, and psychosocial adjustment to epilepsy.

The collaborative role in major medical centers is clear and is readily used in surgical and outpatient evaluations. Neuropsychological testing in children with epilepsy for pre-surgical evaluation is the standard of care and when combined with imaging improves the prognosis for postoperative seizure relief [7]. Neuropsychological testing can also be used to help lateralize the seizure focus, predict risk for postoperative cognitive impairment, establish a baseline in which to measure change and discuss prognosis, and diagnose potential psychiatric issues that impact the patient with the ability to cooperate with the epilepsy surgery process [7]. The same benefits can also be gleaned in non-surgical cases.

In the context of an evaluation, the neuropsychologist typically provides feedback to the child and family and provides recommendations with regard to treatment and rehabilitation. The role of neuropsychological evaluation and its' importance is well understood. However, utilization of neuropsychologists varies

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depending on perceived need, awareness, and access.

## International Stance on Epilepsy and Collaboration with Neuropsychology

The International League Against Epilepsy (ILAE) indicates routine neuropsychological screening for cognitive and behavioral difficulties at epilepsy onset [8]. Full evaluation is recommended when there are signs or symptoms of focal cognitive impairment, if there is a question of neuro developmental delay, behavioral or learning difficulties, cognitive decline, and when information on the effects of the specific seizure disorder and its treatment is desired by members of the care team. The ILAE does not discuss the role of neuropsychology consultation as it pertains to being part of the comprehensive team. However, the neuropsychologist has the potential to play a more pivotal role in consultation and brief intervention, but these areas are less emphasized in the literature and clinical guidelines.

## Recommendations for Improvement and Barriers

Due to the high levels of comorbid complexities, professionals and educators are often left feeling confused, resulting in children with epilepsy being misunderstood. This misunderstanding of pediatric epilepsy and confounding factors is an ideal area for neuropsychologists to provide consultation that will help care providers and educators adjust treatment and educational programs to the changing needs of the individual [9]. Some of these areas are being addressed in major medical centers, but are sporadic when this is not accessible. Table 1 below outlines ways to improve the understanding and treatment of pediatric comorbidities in various areas. The status of team-based care varies from one context to another. For example, some major medical centers may perform exemplary team-based care, but there are many other circumstances where this is not occurring due to financial restraints, provider access, and rural setting.

It is important to understand the benefits of improving the consultative role. Table 2 provides qualitative examples of how neuropsychologists could be better utilized in consultative roles. This is not exhaustive and only used to illustrate specific examples.

Given that unreimbursed time is a consistent barrier to consultation, it is important to identify strategies to address this. The importance of neuropsychological evaluation and consultation needs to be a priority when discussing value-based payment models. Neurologists play a pivotal role in the development of these models and structures and it is imperative for them to advocate for continued and increased involvement of neuropsychology. Other reimbursement strategies would be to preauthorize up to 8 units (2 hours) of case management time during a neuropsychological evaluation and to invite educators to feedback sessions. Time is important, but the importance of going a step further and discussing case details with team providers adds value and improves outcomes.

Although research exists with regard to the importance of neuropsychology in pediatric epilepsy, the mechanisms in neuropsychology consultation in association with improved outcomes are not well known. Future research into the consultative role of neuropsychology in pediatric epilepsy and its' association with improved outcomes would further identify the importance of neuropsychology which may lead to increased utilization.

Those who are training the next generation of neuropsychologists need to emphasize the importance of consultation in pediatric epilepsy care. Neurology and neuropsychology lead trainings in pediatric epilepsy aimed at other professionals will allow for more subspecialty care.

## Conclusion

Collaborative team-based care, including neuropsychological evaluation, in the management of pediatric epilepsy is widely appreciated but not always utilized for a variety of factors. Increasing the role of neuropsychology in the care of pediatric epilepsy will improve precision of appropriate interventions, thus having a direct impact on outcomes and value-based reimbursement models. Recognition of the potential adverse impacts of not receiving appropriate care has life-long consequences on the individual, family, community and healthcare. This should be reason enough to emphasize neuropsychology in team-based collaborative care.

**Table 1:** Current status of comorbidity identification and utilization, areas for improvement and barriers to increasing awareness and improving care in pediatric epilepsy.

Area of Consultation	Current understanding and utilization of Comorbid Complexities in various areas	Recommendations for improvement involving Neuropsychological Consultation	Barriers
School	-Most likely have a Seizure Safety Protocol, often generic. -May or may not have an IEP or 504-plan -Disconnected and fragmented communication	Create recommendations specific to the child's seizures and cognitive and behavioral sequelae and to incorporate into educational planning.	-Extra and uncompensated time -Neuropsychologist may not be established on care team.
Mental Health & Social Work	Disconnected care fragments communication and utilization of seizure and sequelae-based information from being incorporated into treatment planning.	Contact provider and discuss seizure and sequelae-based information and implications to treatment.	-Extra and uncompensated time
PCP	Disconnected care fragments communication and utilization of seizure and sequelae-based information from being incorporated into treatment planning.	Create template for a PCP to use with regard to communicating seizure and sequelae-based information.	-Extra and uncompensated time
Rehabilitation (Occupational, Speech and Language, Physical Therapies)	Disconnected care fragments communication and utilization of seizure and sequelae-based information from being incorporated into treatment planning.	Contact provider and discuss seizure and sequelae-based information and implications to treatment.	-Extra and uncompensated time
Neurology	Disconnected care fragments communication and utilization of seizure and sequelae-based information from being incorporated into treatment planning.	Communicate regarding sequelae-based information to inform treatment	-Extra and uncompensated time
Training	Beyond medical doctors and neuropsychologists, very few professionals obtain knowledge of Epilepsy to inform a subspecialty area of practice.	Establishing relationships with other medical providers, rehab and mental health providers, and educators to provide training and referral streams will increase subspecialty care.	-Extra and uncompensated time. Few systemic training structures in place to promote sub specialization.

**Table 2:** Examples of how neuropsychology consultation improves care.

Area of Consultation	Neuropsychological Consultative Role	Potential Benefit
Inpatient	Aide in the evaluation of psychogenic non-epileptic seizures (PNES). Help differentiate between conversion disorder and factitious disorder after the neurologist has established events are non-epileptic via EEG. These diagnoses required different treatments. This could allow for brief intervention from a neuropsychologist and more precise intervention for an outside provider such as cognitive behavioral therapy. Neuropsychologist to discuss diagnoses and evidence-based treatment with outpatient provider.	-Specific treatment plan when leaving hospital -Reduction in PNES events resulting in less medical utilization -Better quality of life for individual
School	-Outline Challenges of Epilepsy in General -Patient Specific Profile: Seizure type – -Frequency, duration, severity -Identify pre/inter/post ictal states (i.e. post ictal amnesia) -How to identify transient cognitive abilities -How to identify your child's seizures -How seizures impact child's behavior, learning, and cognition -Impact of AEDs on student -Devise a plan around the aforementioned	-More specific plans around neurocognitive and emotional/behavioral challenges -Better academic outcomes -Better awareness of seizures and sequelae -Less stigma and decrease bullying victimization
Mental Health	Help patient, family, and mental health provider understand how a child's epilepsy may be associated with their mental health. Example: a person's panic symptoms may be a pre ictal state of a temporal lobe seizure (when seizure foci align with semiology). Simple partial and complex partial seizures are confusing seizure types for people without knowledge of epilepsy.	-Decrease misdiagnosis and treatment of mental disorders. -Improve precision of diagnoses and better informed treatment.
PCP	Create a template for a PCP to incorporate into their care involving: -Patient Specific Profile: Seizure type – -Frequency, duration, severity -Identify pre/inter/post ictal states (i.e. post ictal amnesia) -How to identify your child's seizures -How seizures impact child's (behavior/learning/attention/concentration) -Impact of AEDs on student	Improve PCP's ability to communicate seizure status and sequelae to other providers. -More useful in rural areas.
Rehabilitation (Occupational, Speech and Language, Physical Therapies; tutoring)	Discuss neuroanatomical and functional correlates with appropriate rehabilitation professional to improve understanding of underlying cognitive sequelae. -Help family prioritize interventions given they often receive multiple recommendations from various providers.	-Improve precision of interventions and effectiveness. -Decrease over utilization of interventions and decrease acute and long-term costs.
Neurology	Communicate regarding neurocognitive sequelae of a condition. For example, through serial evaluations associated with Electrical Status Epilepticus of Sleep (ESES) it will help determine whether a neurological treatment should be adjusted.	The neurologist will gain hard data to support a different treatment option to better control or alleviate effects of ESES. -Decrease the severity of neurocognitive severity associated with ESES.
Training	Provide community trainings and outreach regarding neurocognitive and emotional/behavioral sequelae associated with Epilepsy.	-Improve awareness will result in more informed treatment for professionals but also for families when accessing care.

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