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## **Pediatric Seizures: Access and Utilization of Specialty Care and Mental Health Care**

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PEDIATRIC SEIZURES: ACCESS AND UTILIZATION OF SPECIALTY CARE AND  
MENTAL HEALTH CARE

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A Clinical Research Project submitted to the faculty of the Clinical Psychology Department of  
Augsburg University in partial fulfillment of the requirements for the degree of Doctor of  
Psychology in Clinical Psychology

Minneapolis, Minnesota

JULY 2022

### **Acknowledgements**

Throughout the completion of this project, I have been abundantly supported by faculty, family, and friends; I truly could not have done it without them.

First, I would like to thank my committee for their valuable guidance throughout my studies. Dr. Margit Berman went above and beyond to help me learn and achieve my academic goals. She taught me to have a critical eye in evaluating research, reminded me of my grit, and held me accountable to my aspirations. Dr. Abby Hughes-Scalise helped me establish thoughtful research questions examining a population of interest to me and encouraged me when I needed it most through multiple academic obstacles. Dr. Marcia Bennett has been a helpful guide throughout my academic journey, her wisdom helped me not only in this research, but consistently provided helpful feedback to develop my writing.

My community of friends and family provided sympathetic ears, encouraging words, and practical support while I worked to complete this project. I am now looking forward to our future activities and adventures where I won't have a computer in front of me!

Lastly, but most importantly, I would like to thank my beloved husband who is my very best friend, my rock, and my #1 fan. Without him, I truly believe I would not have succeeded in achieving this goal. He encouraged me when obstacles arrived, made me food when my brain got hungry, had patience when stress got the best of me, and affirmed me every step of the way.

Thank you for being the best partner in life.

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### Abstract

Epilepsy is the leading neurological disorder among children, and requires specialized health care (Zack & Kobau, 2015). However, many patients with seizures do not receive appropriate specialized care (Begley et al., 2009; Burneo et al., 2009). This study examined the impact of health insurance type on access to and use of specialty care and mental health care among pediatric patients, ages 3-17, whose parents reported that they had experienced at least one seizure in the last year. This study was a secondary analysis of data collected in the 2011 (n = 77) and 2016 (n = 87) National Health Survey and investigated whether having private, public, or no insurance affected these children's access to and utilization of specialty and mental health care. It was hypothesized that children with private insurance would have greater access to and utilization of both types of care. Whether severity of mental health symptoms among these children affected mental health care was also investigated, with the hypothesis that those with more severe symptoms would have less access and utilization. Changes in the relationship between insurance type and mental health care over time were also investigated, with the hypothesis that the disparity in access to and utilization of mental health care among participants who had private vs. public health insurance would be larger in 2011 than in 2016. Contrary to these hypotheses, there were no significant differences in access to and use of specialty care and mental health care across insurance types (public, private, and non-insured). Mental health severity was significantly associated with participants' access and use of mental health care, but the relationship was positive, not negative as hypothesized. There were no significant differences between 2011 and 2016 in participants' access to and use of mental health care. Insurance type, symptom severity, and changes related to Affordable Care Act implementation may only be a small factor in disparities of care affecting pediatric seizure patients.

## Chapter 1: Introduction

### Nature of the Problem

Epilepsy is a neurological disorder characterized by recurrent seizures, which are caused by abnormal brain activity and result in periods of unusual behavior (Mayo Clinic, 2020).

Seizures are a symptom of many disorders and not a disease in themselves; however, of those who have seizures with no known cause, approximately half will have a second seizure (Epilepsy Foundation, 2014). Epilepsy is considered a diagnosis after a second unprovoked seizure has occurred. Based on data collected by the National Survey of Children's Health (NSCH), epilepsy is the most common neurological disorder in children and adolescents, affecting approximately 10 out of 1000 children (Russ, Larson, & Halfon, 2012; World Health Organization, 2019; Zack & Kobau, 2015). Epilepsy has been researched for centuries and was originally thought to be a disease caused by negative spiritual forces, until Hippocrates proposed that the symptoms derived from a brain disorder in the late 4<sup>th</sup> Century B.C. (Baloyannis, 2013; Lewis, 1934). Today, pediatric epilepsy is known to cause lifelong neuropsychological and social impairments (Camfield & Camfield, 2007).

Medical management of the disorder has greatly improved over time, and approximately 70% of epilepsy patients will achieve freedom from seizures with proper treatment (Thurman et al., 2016; WHO, 2019). Those that do not achieve seizure freedom, often go on to have intractable symptoms and may be classified as treatment-resistant (Ivanova et al., 2010). Unfortunately, even after seizure symptoms remit, patients with epilepsy still experience medical, psychological, and social handicaps (Camfield & Camfield, 2007; Billakota, Devinsky, & Kim, 2019). Those with epilepsy generally need continuous medical care and caregiver involvement throughout the lifespan (Wagner & Smith, 2007). However, access and utilization

of this care throughout the lifespan are often impaired by barriers to treatment (Begley et al., 2009; Burneo et al., 2009).

### **Associated Comorbidities**

In addition to continued medical problems, patients with epilepsy have a high prevalence of co-occurring psychiatric and neurocognitive disorders. The most common co-occurring psychiatric problems for epilepsy patients are anxiety and depressive disorders (Caplan et al., 2005; Ettinger et al., 1998; Jones et al., 2007; Tellez-Zenteno et al., 2007; Vega et al., 2011). Unmanaged psychiatric symptoms can interrupt anti-epileptic drug (AED) adherence (DiMatteo, Lepper, & Croghan, 2000), impair overall quality of life (Baca et al., 2011; Boylan et al., 2011; Johnson, Jones, Seidenber, & Hermann, 2004; Stevanovic, Jancic, & Lakic, 2011), and increase risk of suicidal ideation (Caplan et al., 2005; Coppola, Operto, Matricardi, Verrotti, 2019). Predictors of the development of psychiatric disorders in epilepsy patients include: younger age at epilepsy diagnosis (resulting in longer duration of epilepsy symptoms; Oguz, Kurul, Dirik, & Eylul, 2002), diagnosis of generalized idiopathic epilepsy (as opposed to focal epilepsy with known etiology; Aliyeva, Aliyev, Mammadbayli, & Aliyeva, 2019), behavior difficulties prior to epilepsy diagnosis (Austin et al., 2001), and other demographic factors such as low socioeconomic status (Austin et al., 2001; Hoie et al., 2005; Wagner & Smith 2007). Evidence-based treatment for psychiatric disorders in patients with epilepsy is limited and even more limited for pediatric patients. Suggested treatments include education programs, (Mittan, 2009), adapted psychotherapies (Coppola et al., 2019), and a combination of AEDs and psychotropic drugs (Mula, 2013).

The most common co-occurring neurocognitive problems for epilepsy patients are Attention Deficit Hyperactive Disorder (ADHD), memory impairment, and cognitive slowing

(Berg et al., 2007; Van Rijckevorsel, 2006). The effects of cognitive impairments are interconnected with psychiatric difficulties, but the severity of such impairments collectively impacts the course and trajectory of treatment outcomes and quality of life (Baca et al., 2011; Davies, Heyman, & Goodman, 2003; Equizabal Love et al., 2016).

Patients who are provided adequate health care generally see a decrease in seizure frequency (Caplan et al., 2005; Mittan, 2009). This in turn improves psychiatric symptoms, cognitive functioning, and quality of life (Davies et al., 2003; Hermann et al., 2008; Kimiskidis & Valeta, 2012; Ott et al, 2003), therefore, stressing the importance of comprehensive specialty care that includes mental health services.

### **Lack of Specialty Care**

Primary care is the first line of treatment for patients with epilepsy, but children with this disorder need a level of specialty care that is often not provided to them (Skinner & Mayer, 2007). For the current study, specialty care will be defined as specialty neurology care and mental health care services. Unfortunately, for many patients with special health care needs, even primary care is often difficult to access (Mayer, Skinner, & Slifkin, 2004). The referral process, societal barriers, and insurance coverage make access to specialty care extremely difficult (Bisgaier & Rhodes, 2011; Burneo et al., 2009; Schiltz et al., 2013; Young, et al., 2002). Research suggests that those who are privately insured have greater access to and utilization of specialty care (Bisgaire & Rhodes, 2011; Halpern, Renaud, & Vickery, 2011; Mayer et al. 2004). In addition to insurance, other barriers impact access and utilization of specialty care, such as level of education (Burneo et al., 2009), social stigma (Thomas & Nair, 2011), and lack of additional resources (Begley et al., 2009).

### **Health Care Disparities**

Lack of insurance coverage and increasing medical costs for neurological services and medications result in higher out-of-pocket fees and greater disparities in care (Callaghan et al., 2019). This problem can be fatal for patients with epilepsy because lack of care is often linked to treatment non-adherence. Treatment non-adherence may negatively impact seizure frequency, exacerbate psychiatric problems and suicidal ideation, and lead to continued medical complications or death (Dimatteo et al., 2000; Jones et al., 2013; Kimiskidis & Veleta, 2012; Thurman et al., 2016). Current research in this area suggests that those who are privately insured have better access to care and lower out-of-pocket fees compared to publicly insured patients (Halpern et al., 2011; Thurman et al., 2016).

### ***Affordable Care Act***

The United States health care system has drastically changed over the last decade with the implementation of the Affordable Care Act (ACA) in 2010. The ACA provided more affordable health insurance options to the most underserved populations, including young adults and those with specialty care needs (Monaghan, 2014). Some research suggests that those needing specialty care are still underserved despite the expansion of coverage as a result of the ACA (Dorner, Jacobs & Sommers, 2015). It is unclear if the ACA has had a positive impact on disparities in pediatric populations with specialty health care needs. According to research conducted after implementation of the ACA, pediatric populations and those who need specialty medical services still experience difficulties in accessing care. These disparities have systematic impacts leading to higher national health care costs, increased mental health problems, and risk of other health related issues (Bisgaier & Rhodes, 2011; Hovinga et al., 2008; Monaghan, 2014; Thurman et al., 2016). Closing the gap in care disparities for youth populations will lead to a

healthier adult population in the future. Pediatric patients with epilepsy who have adequate access to health care during childhood will likely be able to decrease their level of care and number of medications in adulthood, resulting in decreased cost and better health (Kobau, Cui, & Zack, 2016; Modi, Rausch, & Glauser, 2014).

Coverage of mental health care was expanded under the ACA after the implementation of the Mental Health Parity Act of 2008 (Barry & Huskamp, 2011). Unfortunately, the lack of integrated care for those with mental health needs and adult epilepsy continues to result in the underutilization of psychiatric services (Thurman et al., 2016). Examining this gap in pediatric epilepsy populations may provide insight and encourage research and development of integrated psychiatric care with specialty clinics and primary practitioners.

### **Importance for Clinicians**

Examining how pediatric patients who have experienced seizures use and access specialty care will help future practitioners, researchers, and policymakers close the health care disparity gap. Evaluating mental health care access may encourage more comprehensive health services for this population by educating future psychologists regarding the need for seizure-focused treatment. The lack of adequate mental health care highlights the need for population-specific research and mental health practices. Knowledge of specialty care disparities is also important for evaluating the implementation and outcomes of the ACA. If disparities have remained unchanged, then there is more work to be done in implementing best health care practices and insurance opportunities. If disparities have decreased, then there is a positive indication that this policy and associated legislation may be a step in the right direction for better access to care and evidence to support continuation of such policies.

**Research Aims**

This study aims to examine the relationship between insurance type and access to and utilization of specialty care for children who have experienced a seizure within the last 12 months. As noted, ‘specialty care’ is defined as non-primary care, including specialty neurology care and mental health services. Furthermore, this study will investigate whether mental health symptom severity impacts the utilization of mental health care. This research aims to examine if disparities in access to and utilization of mental health and specialty neurology care have improved between 2011 and 2016 for children who experience seizures. As previously noted, epilepsy is only diagnosed after the patient has experienced at least two unprovoked seizures. As such, this study consists of a sample of children who have had at least one seizure but may or may not have a diagnosis of epilepsy. However, studying a sample of those who have experienced seizures is beneficial in evaluating the health care terrain for those who have an epilepsy diagnosis because it will provide valuable information regarding the access to and use of specialty and mental health care in a population that is known to be at risk for continued seizures and other health complications (Epilepsy Foundation, 2014).

## Chapter Two: Literature Review

### Seizure and Epilepsy: Prevalence and Course

Seizures consist of motor and non-motor symptoms. Motor symptoms can include but are not limited to jerking, muscle limpness, muscle tension, and twitching. Non-motor symptoms can include changes in sensation, emotions, thinking, or catatonic behaviors (Epilepsy Foundation, 2017). Seizures are classified into three major groups differentiated by the type of onset. These groups are further divided into different seizure types. The three groups are generalized onset, focal onset, and unknown onset (Fisher et al., 2017). Approximately 10% of the world population will have at least one seizure at some point in life (WHO, 2019). One seizure does not constitute a diagnosis of a seizure disorder. Approximately 48 of every 100,000 children experience febrile seizures, which are most often provoked by fevers. This is the most common form of seizures in childhood, and many of these children do not go on to have a second episode (Okubo & Handa, 2017). Approximately 4-5% of children who experience a febrile seizure go on to be diagnosed with epilepsy (Leung, Lun Hon, & Leung, 2018). Febrile seizures most often occur prior to five years of age and peak at 18 months (Okubo & Handa, 2017; Patterson, Carapetian, Hageman, & Kelly, 2013). Therefore, seizures that occur outside of this window are less likely to have been provoked by fever, which may indicate alternative etiology and trajectory.

Epilepsy is diagnosed after a person experiences at least two unprovoked seizures (Epilepsy Foundation, 2014) and is defined as “a disease characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological, and social consequences of this condition” (Fisher, 2014). Epilepsy affects approximately 50 million people worldwide (Aliyeva, 2019; Thomas & Naire, 2011) and approximately 3 million

U.S adults and over 470,000 American children. Epilepsy is the most common neurological disorder in pediatric patients (Zack & Kobau, 2015). Child-onset epilepsy presents many challenges that may result in lifelong neuropsychological problems.

Epilepsy itself is complex, as it has multiple etiologies, many presentations, and can cause co-occurring neuropsychological and psychiatric deficits (Austin & Caplan, 2007; Fastenau et al., 2009; Wirrell, Grossardt, Wong-Kisel, & Nickels, 2011) which impact occupational, interpersonal, and social functioning (Centers for Disease Control and Prevention (CDC), 2013). Epilepsy does not always present the same way in all patients on diagnostic measures such as EEG, and there are no evidence-based treatment methods or medications that are completely effective for all patients (Davies et al., 2003; Mula, 2013; Mittan, 2009; Shorvon, 2011). Even though more than two-thirds of patients with epilepsy are likely to achieve seizure freedom (Camfield et al., 1993; Thurman et al., 2016), the disorder and its sequelae often have lifelong implications (Camfield & Camfield, 2007). These complexities make diagnosing, treating, and living with epilepsy difficult (Hills, 2007; Smith, 2005).

### **Complex Etiology in Epilepsy**

Epilepsy etiology is complex, due to the multifaceted nature of the presenting symptoms at seizure onset. Recent classifications of epilepsy are based on known etiological factors and mode of onset (Wirrell et al., 2011). Shorvon (2011) described five main categories of epilepsy adapted from the International League Against Epilepsy (ILA) classifications, including: “idiopathic epilepsy,” an ongoing symptomology that is primarily genetic in etiology; “symptomatic epilepsy,” which can be either primarily genetically caused or caused by a myriad of developmental factors, including developmental anomalies, chromosomal disorders, or other neurological syndromes; “predominately acquired causation,” which includes degenerative

neurological conditions, immune disorders, tumors, head trauma, cerebrovascular disorders and infections, or hippocampal sclerosis as the cause for seizure symptoms; and finally “provoked epilepsies,” which are apparent after significant changes in the body due to events such as fever, menstrual cycle, substance use, sleep cycle and changes in metabolic and endocrine balances. Provoked epilepsies also include “reflex epilepsies,” which are an immediate response to environmental stimuli. Lastly, “cryptogenic epilepsies” have unknown etiology, and these make up the largest etiological group in terms of prevalence (Shorvon, 2011, p. 1054). Furthermore, epilepsies also differ in terms of mode of onset, which can include generalized epilepsy or focal epilepsy. Generalized epilepsy indicates that there is a generalized and bilateral epileptiform discharge that can be visualized on an EEG, and focal indicates that observed abnormalities occur in a specific area of the brain (Wirrell et al., 2011). Properly identifying and classifying epilepsy type is important when predicting possible prognosis of the disorder and potential responses to treatments, as generalized forms of epilepsy are associated with increased cognitive impairments and are more resistant to treatments (Shorvon, 2011; Smith, 2005; Wirrell et al., 2011).

### **Diagnosing Epilepsy**

There are many methods to diagnose epilepsy, and these are often used simultaneously in order to gather enough data to specify seizure type, severity, and possible etiology (International League Against Epilepsy ILAE, 2020). Some of these procedures include a neurological exam, neuropsychological testing, electroencephalogram (EEG), magnetic resonance imaging (MRI) and functional MRI (fMRI, Mayo Clinic, 2020). The most common test to diagnose epilepsy is the use of electroencephalogram (EEG) and video electroencephalogram (VEEG) testing (Epilepsy Foundation, 2014). The use of this test is considered best practice, but at times cannot

be done in time to provide clear results (National Institute for Health and Care Excellence (NICE), 2013). These tests detect electrical activity in the brain, which helps determine seizure type and mode of onset. EEG findings are clearer and provide more information for children, if they are performed within 24 hours of a seizure (Smith, 2005). Research also theorizes that early intervention during a child's development may help decrease negative cognitive outcomes (Rathouz et al., 2014). It is therefore important for children to have easy access to these diagnostic measures due to the time-sensitivity in the diagnostic process.

Magnetic resonance imaging (MRI) is also used to detect brain abnormalities in epilepsy patients (Baca et al., 2013). MRI images also help evaluate prognosis and course, as brain structure and function impact outcomes and treatment response (Hermann et al., 2006, 2010). For example, Spooner et al. (2006) reported that lesions detected by MRI in children with temporal lobe epilepsy can indicate a prognosis of intractable epilepsy.

Examining seizure type during the diagnostic process is a crucial component of determining if a child may have epilepsy. Many will experience a single seizure episode and not go on to have continued seizures. A key diagnostic criterion for epilepsy is two or more unprovoked seizures (Epilepsy Foundation, 2014), and approximately 25-30% of first seizures are classified as provoked (Pohlmann-Eden, Beghi, Camfield & Camfield, 2006). Unprovoked generalized seizures, especially "grand mal" seizures, are more indicative of future incidents or possible previous events that went undetected (Pohlmann-Eden et al., 2006). Lastly, recent literature suggests that some patients who are diagnosed with epilepsy are experiencing psychogenic nonepileptic seizures and have been misdiagnosed with epilepsy (Berg, Altalib, Devinsky, & 2017). This is a complicated aspect of the diagnostic process and further highlights the important differentiation between seizures and the diagnosis of epilepsy.

Neuropsychological testing is also used to diagnose cognitive impairment associated with seizures and epilepsy. This includes extensive cognitive testing. The data collected during neuropsychological testing can be used to isolate and confirm cognitive impairment in specific areas of the brain. In addition to functional assessment, the neuropsychological evaluation process includes behavioral information that is not accessible from viewing brain scans or images (Jones-Gotman et al., 2010).

### **Trajectory of Disorder**

Once a patient is diagnosed with epilepsy, there are a variety of possible trajectories for their seizure symptoms. Approximately 50-70% of patients who are treated with medical intervention will achieve “seizure freedom” (Camfield et al., 1993; Kokkonen, Kokkonen, Saukkonen, & Pennanen, 1997; Kwan & Brodie, 2001; Kwan & Sander, 2004; Thijis, Surges, O’Brian, & Sander, 2019). A patient is considered to have achieved seizure freedom if he or she has had no seizures following an intervention for at least three times as long as his or her pre-intervention seizure intervals (Westover, et al., 2012). Furthermore, some studies show as many as 40-50% of patients go on to achieve seizure remission (Duncan, Sander, Sisodiya, & Walker, 2006; Aguglia et al., 2010), which means they have been seizure-free for a period of time long enough to stop AEDs (Epilepsy Foundation, 2019).

Other patients develop intractable, lifelong symptoms and comorbidities (Ivanova et al., 2010). Younger age at detection of epilepsy, impaired cognitive functioning prior to diagnosis, lack of white matter brain development, and comorbid psychopathology all predict a poorer prognosis (Camfield et al., 1993; Hermann et al., 2008, 2010). For some patients, even though seizures may remit, other difficulties may remain. Continued cognitive impairment and

psychopathology, for example, can result in social hardships and lower quality of life (QOL) (Kobau et al., 2014; Stevanovic et al., 2011).

Children with epilepsy frequently have psychosocial setbacks that persist into adulthood. Adults with epilepsy are often less educated, single, and unemployed (Camfield & Camfield, 2007; Kokkonen et al., 1997). Epilepsy patients often struggle with mental health problems that are associated with lower ratings of quality of life (Baca et al., 2011). Research suggests that those with childhood epilepsy often have lower academic achievement and at times must repeat grades (Kokkonen et al., 1997; Wirrell et al., 1997; Wo, Ong, Low, & Lai, 2017). Academic problems may be due to cognitive impairment, school absence for medical appointments, and/or the effect of psychological problems such as depression and anxiety. Adults with epilepsy are more likely to have comorbid medical, psychological, and cognitive problems compared to patients without epilepsy (CDC, 2013; Strine et al., 2005). Adults who were diagnosed with epilepsy in childhood display poor social maturation and social outcomes compared to patients with other chronic illnesses (Camfield & Camfield, 2007). Due to the chronic nature and continued impacts of epilepsy, approximately 15% of patients need some level of assisted care throughout the lifespan, regardless of intractability or seizure control (Camfield & Camfield, 2007; Wagner & Smith, 2007).

Patients with intractable epilepsy often have even more severe outcomes. These patients continue to experience frequent seizures and do not achieve seizure freedom (Berg et al., 2007; Hermann et al., 2008). Intractable epilepsy has the worst prognosis, and these patients often have more impaired cognitive functioning (Berg et al., 2007), increased psychopathology (Boylan et al., 2011), and the lowest quality of life (Equizabal Love et al., 2016) compared to patients with treatable epilepsy. Given the complex possible etiologies and course trajectories in epilepsy,

avoiding intractable epilepsy and/or associated psychological and cognitive impairment requires adequate access to treatment.

### **Risk Factors for Prognosis: Seizure Frequency, Cognitive Impairment, & Quality of Life**

There are several factors that influence epilepsy course and severity that also correlate with the likelihood of cognitive and psychological comorbidities. Positive indicators for good prognosis include achieving freedom from seizures, having minimal cognitive impairment, and reporting good quality of life. Additional factors that promote a positive prognosis include normal cognitive functioning, age at diagnosis between 1 and 12 years of age, normal brain development, good adherence and response to seizure medication, and treatment affordability (Camfield et al., 1993; Modi et al., 2014; Spooner et al., 2006). Risk factors for poor prognosis include earlier age at of reported seizure onset, early signs of cognitive dysfunction, abnormal brain structure and function, medication non-adherence, drug resistance, and psychiatric comorbidities (Aguglia et al., 2010; Duncan et al., 2006; Faught, et al., 2009; Gomez-Ibanez et al., 2017; Hovinga et al., 2008; Spooner et al., 2006).

### ***Cognitive Functioning***

Cognitive functioning is an indicator of epilepsy prognosis as well as a predictive factor for other outcomes, such as seizure frequency and overall quality of life. Many factors that contribute to worse seizure outcomes also impact cognitive functioning (Fastenau et al., 2009; Herman et al., 2008), and there appears to be a bidirectional relationship between cognitive impairments and epilepsy severity. In general, those with epilepsy have increased cognitive impairment; however, those with more cognitive challenges are also more at risk of other symptoms that moderate seizure severity (Li, 2017).

Research suggests that signs of cognitive impairment, such as academic problems and symptoms of attention deficit hyperactivity disorder (ADHD) at the time of epilepsy diagnosis, are correlated with impaired cognitive maturation trajectory, which means lower academic performance and cognitive functioning relative to one's peers (Hermann et al., 2008). Herman et al. (2008) found that children with no history of ADHD symptoms and no academic problems had normal neuropsychological functioning at the time of epilepsy diagnosis and at 2-year follow up, which was similar to healthy controls. Cognitive problems at the time of diagnosis, on the other hand, were associated with continued neurobehavioral difficulties and predicted a poorer trajectory of other psychosocial symptoms (Hermann et al., 2008; Kobau et al., 2014; Kokkonen et al., 1997).

Furthermore, Fastenau et al., (2009) claimed that taking multiple AEDs, abnormal epileptiform activity on EEG, unknown etiology, and multiple seizures are all associated with poorer cognitive outcomes. Compared to healthy siblings, children with epilepsy who experienced all four risk factors were three times more likely to experience neuropsychological impairment. At times, cognitive abnormalities are a potential antecedent indicator of seizures (i.e., they occur before epilepsy diagnosis), but cognitive development is also impacted by epilepsy symptoms early on.

Rathouz et al (2014) suggested that as children with epilepsy age, neurodevelopment continues in a similar trajectory to healthy controls, but that children with epilepsy typically do not achieve normal cognitive functioning. Over a 6-year period, participants with epilepsy in their study experienced steady cognitive development. However, differences in cognitive impairment compared to healthy controls remained consistent in children who displayed neuropsychological impairment at or before their epilepsy diagnoses. Patients with epilepsy

struggled the most in categories of executive functioning, motor speed, and psychomotor speed, but all areas of cognitive functioning were impacted (Rathouz et al., 2014). This is an important finding because research suggests that executive functioning and other cognitive abilities are the most salient predictor of later quality of life and psychosocial outcomes for patients (Equizabal Love et al., 2016).

### ***Age at Epilepsy Diagnosis***

Earlier age of epilepsy diagnosis or detection, especially identification at infancy, is associated with poorer seizure outcomes, increased cognitive dysfunction, and lower quality of life across the lifespan (Aguglia et al., 2010; Berg et al., 2007; Equizabal Love et al., 2016; Gomez-Ibanez et al., 2017). Aguglia et al. (2010) conducted a longitudinal study with patients diagnosed with temporal lobe epilepsy. Patients who achieved remission status had an older age at seizure onset and were less likely to have had febrile seizures during infancy compared to patients who did not achieve seizure freedom. Gomes-Ibanez et al. (2017) found similar results when evaluating treatment response in patients over 16 years old who had been diagnosed with epilepsy in childhood. Of the epilepsy types observed in Gomes-Ibanez's (2017) study (idiopathic generalized epilepsy, generalized tonic-clonic seizures only, absence epilepsy, and juvenile myoclonic epilepsy), all but absence epilepsy showed a significant correlation between older age at onset and positive treatment response, therefore indicating that older age at epilepsy onset is associated with positive treatment outcomes.

Epilepsy diagnosis in infancy is also associated with later poorer cognitive outcomes for children. Hoie et al. (2005) found that 71% of children in their sample who were diagnosed with epilepsy in their first year of life had severe non-verbal cognitive deficits at the time of the study in 1995, compared to only 45-33% of children who were diagnosed later, between the ages of

two and seven years old. Berg and colleagues (2007) found that participants were more likely to display lower levels of cognitive function if epilepsy was diagnosed before five years of age, compared to participants who were older at diagnosis. Hoie et al. (2005) offered two explanations for this pattern of results. First, those who are younger at epilepsy diagnosis are more likely to have abnormal brain structure, which would impact other areas of cognitive functioning. Secondly, those who are younger at diagnosis will have seizures for a longer period, therefore leading to increased impairment in cognitive functioning. In addition, many compounding variables such as type of epilepsy and medication status through development may impact the trajectory of cognitive impairment (Berg et al., 2007).

### ***Brain Structure***

Brain function and structure abnormalities are also a risk factor for poor prognosis for both cognitive abilities and seizure frequency in epilepsy. One specific brain abnormality with predictive value is temporal slowing on interictal EEG. Spooner et al. (2006) found that temporal slowing was associated with a continued course of uncontrolled epilepsy symptoms in a sample of 77 children with temporal lobe epilepsy. In addition, none of the children in the sample with demonstrated lesions on the MRI were free of seizures by the final follow-up, 7 to 14 years after initial seizure onset, and those with focal slowing on interictal EEG also had persistent seizures at the final follow up. This suggests that the presence of brain lesions and abnormal brain function may be informative prognostic indicators for whether seizures are likely to respond to treatment. Furthermore, Spooner et al. (2006) also suggested that there is a relationship between lesion presentation on MRI (such as those mentioned above) and cognitive and behavior difficulties that appear prior to epilepsy diagnosis.

Hermann et al. (2006) discovered that children who had more severe academic difficulties and cognitive problems also had severe reductions in grey matter in the left occipital and parietal lobes. Similarly, Hermann et al., (2010) found significant differences in white matter development between epilepsy patients and their healthy first-cousin child relatives. Results showed white matter significantly increased in healthy controls over a 2-year period but did not develop much at all in epilepsy patients. In these patients, the lack of white matter development was most noticeable in the frontal lobe. Examining brain structure and function to inform the pathological features of epilepsy takes specialized and knowledgeable providers who are specifically trained in understanding the effects of epilepsy. These types of providers are often not general practitioners. Therefore, patients often require specialized referrals to determine the possible trajectory of their cognitive abilities.

### ***AED Adherence***

The possibility of remission in epilepsy is partially dependent on access to proper treatment options. AEDs are the primary form of epilepsy treatment to decrease seizure frequency and severity, but almost 50% of patients do not adhere to the prescribed regimen (Faught, et al., 2009). Non-adherence to medications often results in uncontrolled seizures that increase in severity (Hovinga et al., 2008). Uncontrolled seizures and increased seizure frequency can have damaging effects on cognition, mental health, and quality of life, and can even lead to death (Faught, 2012; Hovinga et al., 2008). Faught et al. (2009) found that more frequent emergency room visits and inpatient hospital stays were associated with AED non-adherence in a large sample of patients with epilepsy, which indicates that those who do not adhere to medication have worse outcomes and are less likely to achieve seizure freedom. This

same study found that medication non-adherence was largely impacted by health care utilization and cost (Faught et al., 2009).

### ***AED Response***

Drug resistance is another difficulty with epilepsy treatment that impacts aspects of prognosis. Though non-adherence to AED regimens impacts drug response (Modi, Morita, & Glauser, 2008), some patients who are adherent to their medications may simply not respond to AED treatment (Schmidt & Luscher, 2009). Non-response to one AED medication sometimes leads to multiple medications being prescribed. However, the prescription of multiple AEDs is also associated with challenges for patients, such as experiencing increased cognitive difficulties (Faught et al., 2009; Modi et al., 2008; Oguz et al., 2002).

### ***Medication Costs***

Researchers hypothesize that high outpatient costs and barriers to routine treatment interrupt patients' ability to consistently adhere to medications, making it difficult to maintain health (Faught et al., 2009). In addition, neurological medication costs have consistently risen over time, adding additional barriers to adhering to AED prescriptions (Callaghan et al., 2019).

Adding to the complexity for patients and providers, these prognostic factors (e.g., cognitive functioning, age at epilepsy diagnosis, brain lesions, medication adherence, and response) often interact bi-directionally or in combination with one another in idiosyncratic ways for individual patients. Multidisciplinary teams are required to diagnose and evaluate these prognostic factors in order to develop comprehensive and individualized treatment options.

### ***Mental Health Comorbidities***

Psychological comorbidities are often precipitated by a combination of risk factors and ultimately impact the quality of life and social functioning of epilepsy patients. Children with

epilepsy are at higher risk for comorbid psychiatric disorders and cognitive impairments (Tellez-Zenteno et al., 2007). Comorbid neuropsychological problems are impacted by the type of epilepsy (Guilfoyle, Monahan, Wesolowski, & Modi, 2015), seizure frequency (Davies et al., 2003), AEDs (Austin & Caplan, 2007), age at epilepsy diagnosis (Jones et al., 2007), and other demographic variables (Wagner & Smith, 2007). Cognitive dysfunction is correlated with mental health symptoms (Kokkonen et al., 1997). Psychological comorbidity impacts social functioning and quality of life well into adulthood (Speechley et al., 2012). Unfortunately, mental health care for this population is understudied and often overlooked (Gilliam, Hecimovic, & Sheline, 2003). Many practitioners report that they have a lack of knowledge in this area, and treatment options are limited (Cotterman-Hart, 2010; Smith et al., 2007).

### ***Prevalence***

Mental health comorbidities in children with epilepsy are common. Studies indicate between 37% and 60% of children with epilepsy have at least one mental health condition, compared to 6-10% of the general population (Aliyeva et al., 2019; Camfield & Camfield, 2007; Davies et al., 2003; Guilfoyle et al., 2015; Ott et al., 2003; Tellez-Zenteno et al., 2007; Vega et al., 2011). In addition, epilepsy is associated with a higher prevalence of suicidal ideation (Oguz, et al., 2002; Ott et al., 2003; Tellez-Zenteno et al., 2007). One study that used data from the Canadian Community Health Survey found that the lifetime prevalence of suicidal ideation was 25% in people with epilepsy, compared to 13% in people who did not have epilepsy (Tellez-Zenteno et al., 2007). Tellez-Zenteno et al. (2007) used lay interviewers and computer software to assess for multiple disorders based on DSM-IV criteria. In that sample, 23.5% of participants had at least one kind of mental disorder in the last 12 months and 35.5% had a lifetime disorder. Furthermore, 17.4% of epilepsy patients met criteria for major depressive disorder; 23.4% of

participants fit criteria for an anxiety disorder in the last 12 months, and 12.8% fit criteria for lifetime anxiety disorder. Combined disorders were also common: 22.8% of participants had both a mood and an anxiety disorder. The prevalence of psychopathology and impaired quality of life in epilepsy patients is thought to be higher than in many other chronic medical disorders, such as diabetes (Davies et al., 2003; Jones et al., 2007) and asthma (Ettinger, Reed, & Cramer, 2004; Kwong et al., 2016). Davies et al. (2003) conducted a study in the United Kingdom with more than 10,000 children, of whom 67 had epilepsy and 48 had diabetes. They found that 37% of children with epilepsy met criteria for a mental disorder, compared to 11% of children with diabetes, and 9% of the remaining children. A more recent study conducted in the United States found that 25% of the sample of epilepsy patients fit criteria for an anxiety or depressive disorder (La Grant, Marquis, Berg, & Grinspan, 2020).

Many studies suggest three main psychological problems in children with epilepsy, including anxiety, depressive symptoms with suicidal ideation, and ADHD (Davies et al., 2003; Guilfoyle et al., 2015; Jones et al., 2007, Ott et al., 2003). Some children display mental health problems prior to an epilepsy diagnosis, but many develop mental health problems after the onset of epilepsy (Austin et al., 2001; Jones et al., 2007). Psychological disorders impact quality of life and seizure treatment response (Caplan et al., 2005). Even though there is a high prevalence of comorbid mental health problems, many psychological disorders in people with epilepsy go undiagnosed and untreated (Baca et al., 2011)

### ***Predictors of Psychiatric Comorbidities***

Several studies suggest that predictors of co-occurring psychological problems in children with epilepsy include: early age at epilepsy diagnosis (Berg et al., 2007; Guilfoyle et al., 2015; Jones et al., 2007), number of AEDs (Hoie et al., 2005), epileptic encephalopathy (Berg et

al., 2007), antecedent cognitive and behavior problems prior to epilepsy diagnosis, and generalized seizure type (Austin & Caplan, 2007). However, findings are sometimes mixed: One study found that age at epilepsy diagnosis, seizure type, and EEG findings were not related to psychopathology (Oguz et al., 2002). Some research suggests no difference in psychiatric severity or diagnoses between patients with specific seizure types (e.g., cryptogenic epilepsy with complex partial seizures, CPS, vs. primary generalized epilepsy with absence, PGE; Ott et al., 2003) and other research suggests clear difference in psychiatric presentation (e.g., CPS is associated with higher rates of depressive diagnoses vs. PGE is associated with higher rates of anxiety-related diagnoses; Caplan et al., 2005). Discrepancies in the literature may be due to difference in diagnostic instruments, recruitment sources, size of samples, differences in chronicity, type of epilepsy, and the age of children used in the studies (Caplan et al., 2005). Furthermore, these demographic variables are confounding and interconnected, therefore complicating the process of examining them independently. However, observing associations between psychopathology, behavior, and seizure variables is important for treatment and prevention of future problems (Austin & Caplan, 2007).

**Age at Epilepsy Diagnosis.** Early age of epilepsy detection is not only correlated with increased seizure symptoms, but also with increased risk for psychopathology (Ott et al., 2003). Jones et al. (2007) compared a group of children with new-onset epilepsy to their healthy, first-degree cousins, and found that the children with epilepsy had higher rates of anxiety, depression, and ADHD. There were also differences within the epilepsy group: early age of epilepsy diagnosis was significantly associated with a higher prevalence of anxiety disorders, but not with other psychopathology or behavior problems. Furthermore, high rates of psychopathology were observed in all types of epilepsy patients in Jones et al. (2007), but there was a slight increase in

tic disorders in patients with localization-related epilepsy and a small increase in conduct disorders in patients with primary generalized epilepsy compared to other epilepsy groups and the participants' healthy first cousins. Jones et al. (2007) also found that 45% of the patient population demonstrated symptoms of psychopathology prior to seizure diagnosis, as determined by blind interview and detailed medical chart review.

Oguz et al. (2002) found a correlation between epilepsy duration and increased levels of anxiety and depression among children and adolescents with epilepsy (most significantly when the duration of epilepsy exceeded 3 years), but no correlation between age of epilepsy diagnosis and psychopathology. Guilfoyle et al. (2015) also found that a longer time since epilepsy diagnosis was correlated with depression, and Caplan et al. (2005) found that a longer duration of epilepsy symptoms was significantly correlated with suicidal ideation. These studies highlight the chronic nature of epilepsy and the lasting association with psychopathology. Age of epilepsy diagnosis is a risk factor for mental health problems in children with epilepsy. When diagnosed with epilepsy at an early age, children should be annually screened for behavior problems and mood inconsistencies (Vega et al., 2011; Wirrell et al., 1997). This also highlights the point that early treatment is necessary to help curtail psychiatric symptoms.

**Seizure Type.** Epilepsy seizure type predicts psychopathology in some studies, but this finding is not consistent across the literature. Some studies show no significant correlation between seizure type and psychopathology (e.g., Oquz, et al., 2002), some show small effects (e.g., Jones et al., 2007) and others show a clear association between seizure type and psychopathology (Austin et al., 2001; Caplan et al., 2005; Guilfoyle et al., 2015). Austin et al. (2001) found that children with partial seizures had more behavior problems than children with primary generalized epilepsy syndromes. Caplan et al. (2005) examined children with complex

partial seizures (CPS) and childhood absence epilepsy (CAE) and found that children in the CPS group had higher rates of depression, but children with CAE had higher rates of anxiety. These results were in part expected, because patients with complex epilepsy have previously been identified as having additional neurological problems that result in cognitive impairment and increased risk of behavior problems (Hoie et al., 2005). However, these studies only examined up to three types of epilepsy in their samples, and several compared only two groups. Aliyeva et al. (2019) compared psychopathology among adolescent patients with generalized idiopathic epilepsy and those with focal epilepsy and found that depression rates were highest among the generalized idiopathic epilepsy group. It appears that patients with all seizure types can experience psychological problems, but those with generalized epilepsy appear to have the highest rate of psychiatric disorders, likely due to the generalized impact on both hemispheres of the brain and subsequent effects on emotion processing.

**Antecedent Symptoms.** Symptoms prior to epilepsy diagnosis (antecedent symptoms), including cognitive impairment, behavior problems, and possible seizures prior to diagnosis are all correlated with increased risk for psychopathology among epilepsy patients (Austin et al., 2001; Jones et al., 2007). Austin et al. (2001) found that children who had potential seizure incidents prior to an epilepsy diagnosis were at increased risk for subsequent behavior problems. Results indicate 39.5% of the population with seizures prior to diagnosis had clinical behavior problems prior to the first known seizure as well (Austin et al., 2001). However, in Austin et al. (2001) parent report was used to collect information regarding child behaviors prior to the diagnosis of epilepsy. A telephone interview was conducted, and the Child Behavior Checklist (CBCL) was used. More recent literature suggests that this form of data collection may be

confounded by other external variables such as parent psychopathology and family stress, which results in over-reporting of symptoms and under-reporting of quality of life (Berg, et al., 2017).

**AEDs.** AEDs are widely used in the treatment of pediatric epilepsy, but recent research suggests the number of AEDs and specific combinations of polytherapy appear to be correlated with increased depressive symptoms (Guilfoyle et al., 2015). Type of AED is also associated with greater psychological symptoms (Austin & Caplan, 2007). For example, one study (Guilfoyle et al., 2015) found that participants who took valproic acid had greater levels of depressive symptoms. Another (Mandelbaum, Burack, & Bhise, 2009) found that carbamazepine was associated with decreased attention among children with focal seizures. There is some correlation between taking multiple AEDs and psychological problems, but researchers have suggested that seizure control is the single most significant predictor of decreasing psychopathology and behavior problems, and that medication simplicity should not be pursued at the expense of seizure control (Davies et al., 2003; Kimiskidis & Valeta, 2012). Though the potential negative impacts of specific types or combinations of AEDs should not be ignored, the seizure control that results from AED use appears to be beneficial in decreasing future cognitive impairment and psychopathology, leading to better overall quality of life (Davies et al., 2003). It is also possible that the association between psychological problems and AED polytherapy may be a result of more severe symptomology overall in those who are prescribed multiple medications, suggesting that seizure severity is the variable of importance associated with psychiatric problems, not AED polytherapy in and of itself. Close monitoring of AED response can determine if a patient needs additional care or a change in medication. A balance must be achieved between AEDs and psychological side effects in order to achieve seizure freedom and maintain a healthy mental state.

**Cognitive Impairment.** As mentioned above, it is well established that cognitive impairment is associated with epilepsy. The severity of impairment dictates the impact on quality of life and psychosocial health and well-being (Berg et al., 2007; Equizabal Love et al., 2016; Fastenau et al., 2009; Hermann et al., 2008; Hoie et al., 2005; Rathouz et al., 2014). It is not clear if cognitive problems or epilepsy symptoms come first, that is, if the abnormal brain structure and function that causes cognitive impairments are also the cause of epilepsy, or if previous undetected seizures impacted brain function and formation leading to cognitive impairments. Research suggests that when cognitive abnormalities are detected at the time of epilepsy diagnosis they often persist over time and require early intervention (Rathouz et al., 2014). Kokkonen et al., 1997 argues that neurological and cognitive impairment associated with epilepsy are the cause of psychosocial impairments, more than epilepsy itself. Specifically, they argue that epilepsy does not negatively impact children and adolescents, but the cognitive problems that follow multiple uncontrolled seizures cause poor social outcomes. A study conducted by Hermann et al., 2006 showed that cognitive impairment preceded the onset of epilepsy in a subset of children diagnosed with idiopathic epilepsy, and those children so affected demonstrate the most academic difficulties throughout the lifespan compared to those with less neuropsychological impairment. This highlights the importance of neuropsychological testing at the time of epilepsy diagnosis. Patients who display cognitive difficulties prior to seizure onset often have increased psychosocial and neurobehavioral difficulties well into adulthood, even in the context of seizure remission (Berg et al., 2007; Davies et al., 2003; Fastenau et al., 2009; Rathouz et al., 2014; Speechley et al., 2012). Cognitive impairment is so closely tied to seizure outcome and psychological problems that a full assessment to determine cognitive functioning would provide patients and their families with valuable information on

how to best manage epilepsy and psychological symptoms. To do this kind of diagnostic workup, specialized care is likely required.

**Demographic Variables.** Demographic factors such as age, gender, SES, and race are inconsistent predictors of psychopathology in pediatric epilepsy patients (Otte et al., 2003). Some research shows that girls have more difficulties with internalizing problems (Austin et al., 2001; Wagner & Smith, 2007) and other research shows that boys have more difficulties (Hoie et al., 2005). Some studies suggest that younger epilepsy patients experience greater levels of psychiatric symptoms (Guilfoyle et al., 2015) and other studies show adolescents report more symptoms (Caplan et al., 2005).

**Seizure Frequency and Severity.** There is a strong correlation between seizure frequency and psychological problems (Qguz et al., 2002). There is also a complex interplay among seizure frequency, the other risk factors for psychological problems in epilepsy, and psychological problems as an outcome. As the other factors become more severe, seizure frequency is likely to increase as well, leading in turn to even more severe psychiatric problems. Davies et al. (2003) showed that greater number of seizures was correlated with greater psychosocial handicaps.

The risk factors for increased psychopathology in epilepsy just reviewed, including seizure frequency, demographic factors, cognitive impairment, AED use, antecedent symptoms, seizure type, and age of epilepsy diagnosis are each important to recognize in order to better assist the treatment planning process. If pediatric neurologists are aware of the correlations between some of these variables and future psychopathology, then evidence-based mental health treatment may be able to alter a trajectory leading to poor lifelong outcomes (Davies et al., 2003; Guilfoyle et al., 2015).

It is important for pediatric neurologists to help manage symptoms such as cognitive capabilities and medication adherence while being mindful of the various factors that make psychiatric problems more likely. To provide this type of care, patients must be offered specialty neurology appointments that are specific to their needs.

### ***General Physician and Mental Health Provider Training***

Lack of training in epilepsy-specific treatment for mental health providers and lack of efficacious treatments create challenges for epilepsy patients even when they receive appropriate referrals to specialty care. Due to the complex nature of the disorder, a multidisciplinary approach to treatment is needed (Wohlrab et al., 2007; Shih et al., 2020). Unfortunately, primary care physicians report lack of competence in assessing the mental health needs of children with epilepsy, and there is a shortage of mental health clinicians who specialize in epilepsy (England, Liverman, Schultz, & Strawbridge, 2012). Furthermore, mental health practitioners report feeling undereducated in newer AEDs and lack specialty training in epilepsy (Smith et al., 2007). It is reported that 79% of neurologists do not screen for depression in patients with epilepsy, and physicians state that they would screen for psychiatric disorders more often, if they were informed of known available evidence-based treatment options to better improve QOL in patients with epilepsy (Gilliam et al., 2004). Researchers have suggested providing practitioners with more training specific to appropriate evidence-based epilepsy care that emphasizes the disorder's related comorbidities and psychosocial challenges. Provider education can help foster a more comprehensive approach to treating symptoms of epilepsy and its comorbidities (Thurman et al., 2016).

### ***Treatment for Mental Health Problems in Epilepsy Patients***

In addition to lack of appropriate training for clinicians, research on efficacious treatment methods for psychiatric disorders in epilepsy patients is also scarce. Despite the improvement in epilepsy research in the last three decades, there is little known about efficacious psychiatric treatment for epilepsy patients (Davies et al., 2003; Mittan, 2009). Some research suggests that cognitive behavioral and mindfulness therapies are effective modes of treatment in the reduction of psychiatric symptoms and improvement in quality of life for patients with epilepsy; however, these studies are not randomized controlled clinical trials and are not specific to pediatric patients (Mehndiratta & Sajatovic, 2013; Tang, Michaelis, & Kwan, 2014). Lack of a clear evidence-based treatment limits opportunity for referral and continued services, which creates additional barriers to mental health treatment for epilepsy patients. In the absence of specific evidence-based research for multidisciplinary treatment for pediatric patients with epilepsy, providers may want to consider multidisciplinary treatment, adapted evidence-based psychotherapy, education programs for patients and their families, and medication combinations that include AEDs as well as psychiatric medications. This level of care would require appropriate access to multiple specialties and patient care coordination among providers.

**Therapy.** Psychotherapy is a main form of treatment for those with psychological problems (American Psychiatric Association, 2013). Cognitive Behavioral Therapy (CBT) is an individual therapy that helps patients focus on connections between thoughts, feelings, behaviors, and body sensations (Beck, 2011). In using CBT for patients with epilepsy, the goal of this therapy is to learn self-regulation, relaxation, and problem-solving skills to help establish a sense of competence in managing the disorder. Some studies show promising results when adapting CBT to fit the needs of adult epilepsy patients (Macrodimitris et al., 2011; Mula, 2013). Further, mind-body approaches such as mindfulness-based Acceptance and Commitment

Therapy (ACT) have shown significant improvements in seizure control and quality of life in adults with epilepsy. However as mentioned above, pediatric specific research that shows CBT, ACT, and mindfulness to be an effective treatment to improve psychiatric symptoms, quality of life, and seizure frequency are typically of the general population or adult epilepsy populations (Coppola et al., 2019; Tang et al., 2004).

**Educational Programs.** Psychoeducation for children with epilepsy and their families often includes information about the main features of the disorder, the possible risks and outcomes, and side effects of medications, with the goal to empower the patient's self-management abilities (Fitzsimons, Normand, Varley, & Delanty, 2012). This information can help families and patients set realistic expectations, guide establishment of good health practices, and outline a treatment follow-up routine (Guilfoyle et al., 2015). Education programs are also targeted at decreasing family stress and improving the patient's understanding of the disorder (Coppola et al., 2019). Many educational programs have been developed to assist in providing a biopsychosocial model for patients and their families.

The "Be Seizure Smart" program, for example, provides family therapy, medical education by a nurse, and seizure management strategies via telephone (Austin et al., 2002). This program was designed to help educate children with epilepsy and their families in order to reduce the fear that often surrounds the disorder and assist in seizure management. At post-assessment, families had better knowledge about epilepsy and better family functioning compared to scores at treatment initiation (Austin et al., 2002). FaMOSES (Modulares Schulungsprogramm Epilepsie für Familien, or, in English, "modular epilepsy training program for families") is a similar psychoeducational program aimed at educating epilepsy patients and their families through a child's storybook. The program has been implemented in Germany and

Switzerland but has not been assessed for outcome (Wohlrab et al., 2007). The Seizure and Epilepsy Education (SEE) program for pediatric epilepsy patients also demonstrated improvements in these areas and reduced suicidal ideation (Shore, Perkins, & Austin, 2008). The SEE program appeared to reduce children's worries about epilepsy and improve their overall knowledge of the disorder. In general, these programs appear to be helpful in educating pediatric patients and their families about epilepsy symptoms while improving overall mental health symptoms and quality of life (Mittan, 2009).

**AEDs and Psychopharmacological Treatment.** Psychotropic medication and AEDs are often used in combination for treatment of psychiatric disorders in epilepsy patients (Coppola et al., 2019; Mittan, 2009; Mula, 2013). Mandelbaum et al. (2009) found psychological improvement in children with focal seizures over 12 months of AED treatment. However, children in this study diagnosed with primary generalized seizures did not see the same benefit; psychological symptoms in this group remained stable. Despite these benefits, it is difficult to determine if AED treatment itself is helpful in decreasing psychopathology or if the relief from seizure expression is the cause for decreased symptoms of anxiety and depression.

A limitation in the literature is that there are no controlled studies examining psychopharmacological treatment for depressive and anxiety disorders in children and adolescents with epilepsy, and therefore many suggestions related to the use of medications, such as serotonin reuptake inhibitors (SSRIs), are based on research in pediatric patients who do not have epilepsy or adult patients with epilepsy (Coppola et al., 2019). The use of antidepressants and anti-anxiety medications has been controversial in epilepsy patients because several (although not all) of these medications have seizures as a possible side effect (Gilliam et al., 2004). In fact, the only double-blind controlled study that examined the use of antidepressant

drugs in adults with epilepsy was published more than 35 years ago and found no benefit for antidepressant medication over placebo for these patients (Robertson & Trimble, 1985). This study compared three groups of epilepsy patients: one taking nomifensine, another taking amitriptyline, and a placebo control group. The results showed no significant difference in seizure frequency among the three groups (Robertson & Trimble, 1985). Research supporting SSRI treatment in patients with epilepsy have largely come from open trials and in primarily adult populations (Kanner 2003). However, regardless of the type of treatment (psychotherapy, medication, educational programs), it is clear that the treatment of psychological symptoms in patients with epilepsy needs to be prioritized to better assist seizure reduction, AED adherence, and overall quality of life (Boylan et al., 2011; Trang et al., 2014).

### **A Multidisciplinary Approach**

Due to the complex nature of epilepsy as a disorder, the most effective approach to treatment may be multidisciplinary. Orjuela-Rojas et al. (2015) compared CBT to treatment with SSRIs for depressive symptoms in epilepsy patients. There were no significant differences between these two treatments in this study, but both groups showed significant improvements in quality-of-life ratings and improved depressive symptoms after treatment. Mula et al. (2013) suggested that a multidisciplinary approach using both therapy and antidepressants would be optimal to treat depression in patients with epilepsy. There have been no controlled studies examining the treatment outcomes in a group of patients that received multiple forms of treatment simultaneously, but researchers have called for future studies in this area and hypothesize that a combined approach will lead to the best treatment outcomes (Mula et al., 2013; Mittan, 2009; Orjuela-Rojas et al., 2015). There are also no studies of which I am aware that examine patient symptom outcomes when patients are involved in neurology specialty care

and mental health care simultaneously, but researchers theorize that more comprehensive care for this population should be beneficial in reducing psychiatric problems and epilepsy symptoms.

### **Access to Care**

There are many barriers for epilepsy patients attempting to access appropriate health care. It is especially difficult to obtain specialty care, and patients are unlikely to receive mental health treatment. Research conducted prior to or just after the 2010 passage of the ACA indicates that a primary barrier to treatment at that time was insurance coverage (Bisgaier & Rhodes, 2011; Halpern et al., 2011; Skinner & Mayer, 2007). The insurance coverage landscape has changed in the last 10 years, but some research suggests that insurance continues to be a barrier to treatment (Sorin et al., 2019).

Access to primary care is important in referring patients to appropriate specialty care. Specialty care (care delivered by a non-primary care physician, Skinner & Mayer, 2007) is needed to assist in seizure management and reduce psychiatric symptoms. Those who receive appropriate specialty care are more likely to adhere to medications, receive other treatment options, and have greater success in achieving seizure freedom (Modi et al., 2014; Thurman et al., 2016). Unfortunately, many people with epilepsy do not have appropriate access to mental health professionals and neurologists who specialize in epilepsy, resulting in overreliance on primary care practitioners for epilepsy treatment (CDC, 2012; Begley et al., 2009; Mayer et al., 2004).

### **Disparities in Care**

There are large differences in access and utilization of health care between those who are privately insured, publicly insured, and uninsured. In a national survey of children who reported a need for specialty care, 7.3% were unable to obtain the care that was needed (Mayer et al.,

2004). Part of the difficulty in accessing appropriate care is the referral system process known as “gatekeeping”. Gatekeeping requires that a primary care physician be visited in order to obtain a referral to visit a specialty care provider (Skinner & Mayer, 2007, p.3). This is challenging because approximately 4% of children with special health care needs are unable to obtain routine care from a primary physician (Mayer et al., 2004). The restrictions placed on patients visiting out of network providers that are established by private insurance companies create additional barriers in accessing care (Skinner & Mayer, 2007). Some assume that children with special health care needs are more likely to receive appropriate care due to the concentration of specialty providers in academic medical centers, because these settings are often able to provide care to those who may not be able to pay for the entire cost of service (Fleishon, Itri, Boland, & Duszak, 2016). As a result, this may minimize care disparities between Medicaid, private-insurance, and private pay. Research suggests otherwise, however, and accessing specialty care is often a complex process that requires insurance approval and referrals from primary physicians (Skinner & Mayer, 2007).

The impact of insurance on access to care for epilepsy patients in the United States is grossly understudied. Most recent research in the area of health care disparities and epilepsy appears to have been conducted mainly in other countries, where health insurance differs and access to health care is not comparable to the United States (Andersson et al., 2019; Balarabe et al., 2019; Hindley & Jameson, 2019; Kandawasvika, Dingiswayo, Kaisi, & Ngara, 2019). Only a handful of studies have been conducted in the United States in the last ten years, and there have been significant health care changes in the U.S in the last decade. First, the ACA was enacted in 2010, decreasing the overall number of patients who are uninsured (Gold, Newman-Toker, Sharfstein, 2015; Monaghan, 2014). In 2016, Thurman and colleagues conducted a study

analyzing health care access in adults with epilepsy. They examined the National Health Interview Survey (NHIS) from years 2010 and 2013 and found great disparities in care between insurance categories among adult epilepsy patients, even after the enactment of the ACA. Another significant change in U.S health care was the Mental Health Care Parity and Addiction Equity Act of 2008, which required mental health care services be treated with the same importance and insurance coverage as other medical treatments. This helped psychological services become more available than before. In 2010, the ACA ultimately provided the resources for the 2008 parity act to be widely instituted (Barry & Huskamp, 2011).

Based on review of literature accessible, there appear to be no studies examining access to or utilization of care for children with epilepsy in the United States in the last five years. Research examining access to care for epilepsy patients most frequently includes young adult and geriatric populations and consistently excludes pediatric groups (Thurman et al., 2016). This may be because young adults and older adults are those who are most likely to be uninsured and have the greatest disparities in care compared to those who are middle aged or children (Monaghan, 2014). Excluding pediatric patients in these studies leaves children with severe neurological conditions understudied and deemphasized. Patients diagnosed with epilepsy in childhood typically have more serious symptoms and more severe comorbidities. Therefore, evaluating access to care in pediatric samples is imperative in order to bridge gaps in care that impact positive treatment progress.

### **Use of Care**

Patients with epilepsy are more likely to use health care than those without epilepsy. Epilepsy patients have more inpatient stays, emergency department visits, an increased number of outpatient appointments, and increased prescription medications per year compared to those

without epilepsy (CDC, 2012; Ivanova et al., 2010; Mayer et al., 2004). Often children with special health care needs, such as epilepsy, rely on primary care physicians for specialty treatment (CDC, 2012; Begley et al., 2009; Mayer et al., 2004). Primary care alone is insufficient in providing treatment options for children with epilepsy and specialty care is needed in order to supply patients and their families with multidisciplinary treatment options and best care practices. Parents of children with epilepsy may not know specialty care is beneficial or needed if access to primary care is limited (Mayer et al., 2004). Therefore, easy access to primary care or initial medical services is encouraged in order to increase utilization and provide patients with instruction to seek specialty care providers.

#### *Access to Specialty Neurology Care*

Children with epilepsy have special health care needs that require services provided by a neurologist. Mayer et al. (2004) aimed to determine if children with special health care needs had appropriate access to specialty services. They report that 3.2% of patients with special health care needs, including epilepsy, were unable to obtain primary care services and 7.3% reported unmet specialty care services. The unmet need for specialty care was significantly higher than the unmet need for routine care. The Center for Disease Control and Prevention (CDC, 2012) reported that according to the 2010 National Health Interview Survey (NHIS) only “52.8% of adults with active epilepsy” had seen a neurology specialist in the last year (CDC, 2012). Mayer et al. (2004) also showed that children with more severe health care needs were more likely to have difficulty accessing care. Furthermore, children who had disorders that routinely changed or progressed were at a greater disadvantage in accessing specialized care than children who had a stable prognosis. This is important because those with epilepsy often need changes to

medications, additional treatment options, and continued psychoeducation at various points throughout their lives.

To diagnose and classify epilepsy disorders efficiently and effectively, EEG or VEEG are used to observe possible markers for potential prognosis of the disorder. Epileptiform activity on EEG has been shown to be a marker for future neuropsychological impairment (Fastenau et al., 2009; Hermann et al., 2008). Primary care physicians do not typically perform neuropsychological testing and diagnostic imaging (including MRI and EEG) even when they can be obtained in the primary care setting, typically because specialty care physicians are needed to interpret results from these measures. Using these technologies to communicate possible prognosis and potential trajectories is an important component of the treatment planning process but are often not utilized due to the barriers to specialty care (Schiltz et al., 2013; Smith, 2005). Results of these specialized diagnostic measures may help indicate which AEDs may work best (or at all), if surgery may be an option, or if there are other therapies that may be beneficial. Baca et al. (2013) found that children who have had an MRI screening have quicker referrals to surgery, regardless of severity presented on MRI results. Shorter times to surgery are associated with better outcomes post-surgery; therefore, efficient specialty care has important implications (Baca et al., 2013). It is essential that epilepsy patients have easy access to diagnostic measures provided by specialists (e.g., MRI and EEG) in order to inform treatment planning and prediction of possible prognosis. To provide smoother transitions from primary care to specialty care, researchers must first identify and aim to reduce systematic barriers that make this process challenging for patients and their families. One main issue is that there is no standardized process of care for children who experience seizures. Care is variable across the country and there are few specialized clinics. Sorin, Snupp, & Berg (2019) conducted a study

that showed patients often waited weeks after a seizure event to be evaluated by a specialist or be referred to a specialty clinic. They also reported that specialty clinics attributed the delay to insurance barriers, distance families needed to travel, and simply long waiting lists of patients. This furthers the argument that pediatric patients who may have epilepsy are not receiving appropriate and timely care after initial seizure events.

### *Access to Specialty Mental Health Care*

Despite the high prevalence of psychiatric disorders among epilepsy patients (estimates range as high as 50-70%), (Aliyeva et al., 2019; Camfield & Camfield, 2007; Davies et al., 2003; Guilfoyle et al., 2015; Tellez-Zenteno et al., 2007; Vega et al., 2011), health care providers often overlook psychiatric symptoms in epilepsy patients (Aliyeva et al., 2019; Ettinger et al., 1998) and only approximately 30% receive mental health (MH) treatment (Ott et al., 2003; Wagner & Smith, 2007). Ott et al. (2003) identified risk factors for mental health care disparities among children with epilepsy. These factors include “younger age, lower parental education status, AED monotherapy and higher cognitive ability” (Ott et al., 2003, p. 591). Older children in the study were more likely to receive mental health treatment, and those on AED polytherapy were seen as more severe cases and more often referred for mental health care. Thurman et al. (2016) conducted a study examining access to specialty care for adults with epilepsy. These results showed that those with epilepsy were more likely to need mental health services compared to those without epilepsy, but epilepsy patients experienced more barriers to accessing mental health treatment. Guilfoyle et al. (2015) argued that collaborative care between mental health providers (such as social workers, psychologists, and counselors) and neurology specialists would decrease health care utilization, reduce medical costs, and improve quality of life in children with epilepsy. The Institute of Medicine report on “Epilepsy across the spectrum:

Promoting health and understanding” (2012) suggested that mental health should be a primary focus in epilepsy centers and in epilepsy care (England, et al., 2012). Due to the high prevalence and severity of psychiatric disorders in this population, early identification and treatment is necessary. Therefore, research that assesses access to mental health care is particularly relevant.

### **Barriers to Specialty Care**

There are major disparities in care for epilepsy patients, which are caused by a myriad of barriers. Among adults with epilepsy, these include low education level (Yoon, Frick, Carr, & Austin, 2009), unemployment (Burneo et al., 2009), and disability (Thurman et al., 2016). Approximately half of adult epilepsy patients are unable to work and unable to drive (Kobau et al., 2014), limiting their ability to afford necessary services and creating difficulties with transportation (Thurman et al., 2016). Similar barriers are assumed for child populations but are drastically understudied. Another primary barrier to mental health treatment is the stigma that surrounds both epilepsy and mental health treatments (Thomas & Nair, 2011). Neurology specialists are more likely than pediatricians to refer epilepsy patients to mental health care and are often more aware of cultural stigma around the disorder (Smith et al., 2007). Neurologists’ specialized knowledge is another reason why children who have experienced seizures need easy access to specialists who are aware of epilepsy symptomology and are trained in making appropriate referral and treatment decisions.

In addition to low SES, children who are of minority racial status are more often unable to obtain routine health care and specialty health care than that of their White peers (Mayer et al., 2004). Across studies, research suggests that minority groups with epilepsy do not see specialists or primary care physicians as often as White patients (Baca et al., 2013; Begley et al., 2009; Burneo et al., 2009; CDC, 2012; Halpern et al., 2011; Mayer et al., 2004; Schiltz et al., 2013;). In

addition, those of minority status are less likely to be publicly insured which is an additional barrier discussed in a later section (McClelland, Curran, Davey, & Okuyemi, 2007). Another barrier in accessing treatment is low education in adult populations and low parental education in pediatric populations (Burneo et al., 2009; Halpern et al., 2011; Mayer et al., 2004; Ott et al., 2003). Researchers speculate that adults with fewer years of education (as commonly seen in adult with epilepsy) are less likely to be employed by companies that offer private health insurance (Halpern et al., 2011). Level of education may be a proxy for insurance type, indicating insurance may be the root barrier. For children with parents with lower education, researchers speculate that low parental education is likely an indicator of low SES, which may indicate additional psychosocial stressors for the family increasing overall mental health challenges and barriers to treatment (Ott et al., 2003).

### ***Lack of Providers***

Many pediatric neurologists report feeling underequipped to diagnose and treat psychiatric symptoms in epilepsy patients. These physicians also report a limited number of mental health care professionals who are familiar with the complications of epilepsy (Smith et al., 2007). Lack of specialized clinics for epilepsy is also problematic. Patients who are uninsured or publicly insured are less likely to receive specialty care if they live in an area that does not have an epilepsy center. However, this is not the case for privately insured patients who likely have transportation capabilities to travel longer distances for care. If an epilepsy center is available, patients in the area receive more routine specialized care (Schiltz et al., 2013). Schiltz et al. (2013) argues that providing insurance to those uninsured will not improve access to specialized care if there is a shortage of epilepsy centers.

### ***Lack of Education for Providers and Families***

An additional barrier to treatment is the lack of knowledge surrounding epilepsy diagnosis for the patient, the family, and the surrounding community. In a study examining knowledge and attitudes toward epilepsy patients and parents, a sample of college students reported lack of knowledge about epilepsy and showed negative attitudes toward the disorder (Young et al., 2002). Stigma and negative perceptions held by patients and providers add additional obstacles to treatment, especially mental health treatment (Wagner & Smith, 2007). Because of this, patients and families may minimize symptoms surrounding mental health treatment that are stigmatizing, limiting access to and utilization of mental health care (Smith et al., 2007; Thomas & Nair, 2011). Young et al. (2002) showed improvement in perception, attitudes, and knowledge when participants were provided an educational brochure about epilepsy disorder. Psychoeducation such as this is a great way to reduce stigma and expand knowledge around mental health care and epilepsy.

### *Insurance Differences*

Insurance plays a significant role in access to primary and specialty care for patients with epilepsy and other chronic disorders (Bisgaier & Rhodes, 2011; Begley et al., 2009; Burneo et al., 2009; Mayer et al., 2004; McClelland et al., 2007; Skinner & Mayer, 2007; Smith, 2007). There are known differences in care access among those with different types of insurance coverage.

**Public Health Insurance.** Public insurance includes Medicare for those 65 years and older, Medicaid for low-income patients, and the State Children's Health Insurance Program (SCHIP) for children of low income (Skinner & Mayer, 2007). In adult populations, epilepsy patients are more likely to be insured under public insurance (Thurman et al., 2016). Medicare has generous specialty coverage (Skinner & Mayer, 2007), but in pediatric populations, patients

covered by public insurance are less likely to receive specialty services than patients who have private insurance (Bisgaier & Rhodes, 2011). Bisgaier & Rhodes (2011) collected information via telephone survey from eight specialty clinics in a well-populated county. Their results indicated that approximately 66% of pediatric patients covered by public insurance were denied appointments for specialty care by the clinics contacted for the study. This percentage is drastically different from the 11% rejection rate for patients covered by private insurance. For patients with epilepsy, this rejection can be life threatening, as seizure management and psychiatric care received in a timely fashion are imperative to prevent deadly seizures and suicide attempts. If approved for specialty care, children covered by public insurance are more likely to have longer waiting periods before an appointment date compared to those privately insured. In Bisgaier & Rhodes (2011), the wait was 42 days for publicly insured patients and 20 days for privately insured patients. This is significant because research suggests that longer delays from seizure onset to diagnosis and treatment can lead to more severe negative outcomes. Another study examined factors that lead to shorter durations between epilepsy onset and to surgery evaluation and found that those with private insurance were more likely to be evaluated sooner compared to those with public insurance (Baca et al., 2013).

Shiltz et al. (2013) cited research that suggests two reasons for this trend: providers are reimbursed at lower rates when Medicare/Medicaid is used as the form of payment (Cunningham & Nichols, 2005) and there are often a delays or complications in processing payments compared to private insurance (Berman, Dolins, Tang & Yudkowsky, 2002). However, a trend analysis indicates that use of Medicare of annual wellness visits increased between the years of 2011 and 2014 in a random sample of patient participants, which may indicate some effectiveness of the ACA in increasing access to care (Ganguli, Souza, McWilliams, & Mehrotra, 2017).

Though patients with public insurance often have lower out of pocket costs for medications and hospital stays, they are typically prescribed older AEDs compared to privately insured patients (Halpern et al., 2011). This is likely because the newer generation of AEDs are more costly than those put into market prior to 1994 (Beghi, Atzeni, & Garattini, 2008). Callaghan et al. (2019) reported that the costs of neurologic medications have increased overall, especially for those who have high-deductible insurance plans, which force them to bear more of the costs for medications and care. There is evidence to suggest that older AEDs have more negative side effects than new AEDs (Billakota et al., 2019). Guilfoyle et al. (2015) found that children with epilepsy covered by public insurance are at greater risk for more severe psychopathology compared to their privately insured peers. Because public insurance coverage is often an indication of low SES, disparities in use of care between those publicly insured and privately insured may be a result of additional barriers for those of lower SES (Guilfoyle et al., 2015).

**Private Health Insurance.** Private insurance includes “any coverage that is not publicly financed, including employer-based coverage and individually purchased coverage” (Skinner & Mayer, 2007, p.3). In adult epilepsy populations, patients are less likely to be privately insured due to unemployment and disability to work (Thurman et al., 2016). For children, the breakdown is unclear, but, in general, those who have private insurance have more access to care and shorter appointment and referral wait times than those publicly insured or not insured (Baca et al., 2013). Approximately 50% of privately insured adult epilepsy patients visit a neurologist within a year compared to only 14% of uninsured patients (Halpern et al., 2011). Those who are privately insured also have better access to diagnostic tests such as EEG or VEEG (Schiltz, et al., 2013) and referrals to surgery which can lead to better seizure control and treatment options (Baca et

al., 2013). McClelland et al. (2007) found that children with epilepsy who are privately insured are 121% more likely to receive surgery compared to those paying another way.

**Non-Insured.** Uninsured or Non-Insured patients are considered to have “a lack of payment source other than self-pay” (Skinner & Meyer, 2007, p.3). Patients without insurance often have the highest rate of unmet needs for primary health care. This makes accessing specialty care much more difficult (Meyer et al., 2004). Uninsured patients have the least number of outpatient primary care visits, specialty care visits, and emergency room visits. The cost of emergency room visits may deter patients from using this service as the out-of-pocket cost for an emergency room visit is four times the dollar amount for those uninsured compared to those who are insured (Halpern et al., 2011). It can be assumed that because those uninsured are unlikely to see a primary care physician, they are also unlikely to be referred to a specialist for their condition. Begley et al. (2009) found that uninsured epilepsy patients are less likely to use specialty care and more likely to use generalist visits as a form of routine care than those who are privately insured. Uninsured patients are more difficult to study as most health care research is performed in the context of clinics, hospitals, and academic institutions. Children with no insurance have limited access to care and the most barriers to treatment (Skinner & Mayer, 2007).

### *Expenses of Epilepsy Care*

Epilepsy requires lifelong care, often with many prescription medications and caretaker needs. This presents as an economic burden to both the individual and the national health care system. Assessing the individual and national expenses of epilepsy demonstrates additional financial barriers to appropriate care access.

**Individual Expenses.** Callaghan et al. (2019) showed that medications for neurological conditions have increased drastically in cost. Out-of-pocket costs for these medications doubled between 2004 and 2016. This is especially true for patients who have high deductible plans and those uninsured (Callaghan et al., 2019). Those unable to pay for their medications may experience life-threatening repercussions. Non-adherence to AEDs can increase seizure frequency and increase depressive symptoms and suicidal ideation (Dimatteo, et al., 2000; Jones et al., 2013; Kimiskidis & Veleta, 2012; Thurman et al., 2016). Adhering to medication is cheaper than non-adherence for the health care system, as it prevents emergency visits, inpatient stays, laboratory exams, and temporary medication increases (Faight, et al., 2009; Faight, 2012). Halpern et al. (2011) reported that uninsured individuals paid out of pocket \$400 more per year for AEDs than insured patients. Ivanova et al. (2010) found that those with epilepsy have increased direct costs of medical care compared to those who do not have epilepsy. On average, those with epilepsy who are privately insured have approximately \$7,000 more in annual direct costs compared to healthy controls (\$11,200 for patients v. \$4,087 for controls). This is consistent with earlier research that indicated similar figures, approximately \$11,700 for epilepsy patients and \$3,800 for controls (Griffiths et al., 1999). The similarity in figures over time is interesting because it shows little change in the patient cost of care over this period of time, not accounting for inflation or change in medical costs. Begley et al. (1994) projected lifetime cost of epilepsy (in 1990 U.S dollars) was approximately \$4,272 for those who achieved seizure freedom and remission status and up to approximately \$138,000 for those who developed intractable epilepsy. Effective and timely epilepsy treatment can be the differentiating factor in achieving remission status. From an economic perspective, it is more beneficial to provide patients access to effective and adequate primary and specialty care early on in the diagnosis and

treatment process. Ivanova et al. (2010) argued that if appropriate preventative and routine care is provided, the overall cost per patient and other societal costs would decrease due to symptom and medication reduction.

### **Epilepsy, Insurance, and Access to Care: A Gap in Knowledge**

The information discussed, thus far, has presented several important issues. First, epilepsy is a complicated and chronic disorder and specialty neurology care is needed to best treat symptoms (Skinner & Mayer, 2007). Research examining unmet needs for routine specialty care is minimally researched in epilepsy groups (Mayer et al., 2004). Second, comorbid psychiatric problems are prevalent among those with epilepsy (Caplan et al., 2005; Jones et al., 2007). Ideally those with epilepsy would receive effective and timely mental health treatment, but unfortunately many do not (Baca et al., 2011). Evidence based treatments are understudied in epilepsy populations and many mental health providers feel underequipped to treat those with epilepsy (Davies et al., 2003; Mittan, 2009). Third, insurance type impacts cost (Skinner & Mayer, 2007), timeliness of treatment (Bisgaier & Rhodes, 2011), and overall access and utilization of care for patients with epilepsy (Halpern et al., 2011; Schiltz et al., 2013). Research is sparse in examining these factors in pediatric populations (Skinner et al., 2007) and no research has been conducted in the last decade, specific to this group. The lack of recent research pertaining to insurance type is significant because there have been drastic changes in health care policy in the United States since 2008 (Monaghan, 2014).

Thurman et al. (2016) encouraged continued research in these areas and suggests that results could lead to policy recommendations to better provide for those with chronic comorbid disorders. Thurman et al. (2016) used the 2010 and 2013 NHIS data to examine access to and utilization of health care in adult epilepsy patients. Inclusion criteria for this study required a

positive response to a question that asks if a physician has diagnosed the participant with epilepsy. Other variables included a categorical grouping of insurance type, a mental health symptoms scale, dichotomous responses to questions regarding health care access, and dichotomous responses to questions that address socioeconomic barriers. The results of this study indicated that adults with epilepsy were more likely to be uninsured or publicly insured compared to adults without epilepsy. Further, those publicly insured or uninsured had less access to care than those who were privately insured. In addition, this study found that many participants with epilepsy were unable to afford many aspects of health care. Participants also had high rates of psychiatric comorbidity, arguing the need for more available mental health services for this population. When comparing the years 2010 and 2013, Thurman et al. (2016) did not find a significant difference in access to health care among adult epilepsy patients. Therefore, in this present study, the data used will be more recent with intention of capturing a significant difference between years.

### **Research Rationale**

Epilepsy is the most common neurological disorder in pediatric patients. This disorder is complex in nature, difficult to treat, and has lifelong psychosocial impacts. The course and trajectory of the disorder are individualized, and the possibility of remission is partially dependent on access to proper treatment options. Those with epilepsy are more at risk of psychiatric disorders and need specialized care throughout their lifespan. Psychological comorbidity is often precipitated by a combination of risk factors and ultimately impacts the quality of life and social functioning. The research on efficacious treatment methods for psychiatric disorders in epilepsy populations is scarce, and many practitioners lack training in epilepsy-specific treatments. Due to the complex nature of the disorder, a multidisciplinary

approach to treatment is needed and should include both specialty neurology care and mental health care.

As noted in the literature review for this study, many patients will experience a single seizure and not go on to experience recurrent episodes, and one seizure does not fit the criteria for an epilepsy diagnosis (Epilepsy Foundation, 2014; Okubo & Handa, 2017). This is important to note as this study examines children whose parents have reported that they have experienced at least one seizure in the last 12 months, but the survey does not go on to clarify if the child has had multiple episodes or if the child has a diagnosis of epilepsy. Using the NHIS has benefits in that it will provide a wide range of participants from different geographic regions, socioeconomic statuses, races, and ethnicities. This sample also has limitations in that it is unclear if a child who endorsed seizures in this sample has an epilepsy diagnosis or may go on to be diagnosed with epilepsy later. Understanding seizure care is helpful in highlighting areas in which care may need to be improved or areas in which care is sufficient. Examining access to and utilization of specialty care and mental health care can inform research at large by identifying health care trends. This research can inform clinicians about a wider range of child populations with specialty care needs.

This present study aims to examine the relationship between insurance type and access to and utilization of specialty care in a pediatric sample who has experienced seizures. Additionally, this research aimed to examine if access to specialty care had changed between 2011 and 2016 for those who report seizures, to assess the impact of the ACA on pediatric seizure care. The 2011 data set was used along with the 2016 dataset for their similarity in survey questions pertaining to access and utilization of care. Data from 2016 was used for the first three hypotheses independently and then compared to data from 2011 for the fourth hypothesis. Data

from 2016 provides a unique timepoint because information was collected after the enactment of the ACA and prior to any health care changes initiated by the Trump administration in 2017. Observing the 2016 data independently from other years provided an isolated look at policy changes specific to this period. Further, questions on the NHIS differ from year to year and the questions related to access and use of care were not similar among all years.

The first aim of this study was to investigate whether type of health insurance in children who report seizures relates to access and utilization of specialty care. Hypothesis 1 related to this aim was that, in 2016, children who had experienced seizures in the last 12 months and had private health insurance would have greater access to and utilization of specialty care compared to those who were publicly insured or uninsured in 2016, whereas those who were uninsured would have less access to and utilization of specialty care compared to those publicly insured.

The second aim of this study was to investigate whether type of insurance in children with seizures relates to access and use of mental health care. Hypothesis 2 related to this aim was that, in 2016, children who had experienced seizures in the last 12 months and had private health insurance would have greater access to and utilization of mental health care compared to those who were publicly insured, or uninsured, and that those who were uninsured would have less access to and utilization of mental health care compared to those privately insured or publicly insured.

The third aim of this study was to investigate whether mental health symptom severity impacts access to mental health care. Hypothesis 3 related to this aim was that participants with more severe mental health symptoms would have less access to and utilization of mental health care compared to those with less severe mental health symptoms.

The fourth and last aim of this study was to investigate whether disparities of specialty health care access between patients who are privately insured and publicly insured have changed from 2011 to 2016 among pediatric populations who experience seizures. Hypothesis 4 related to this aim was that the disparity in access to and utilization of mental health care among participants who had private vs. public health insurance would be larger in 2011 than in 2016.

### **Chapter 3: Methods**

#### **Procedures**

The National Health Interview Survey (NHIS) is a major data collection program facilitated by the Centers for Disease Control and Prevention. The NHIS is a cross-sectional household interview survey given to non-institutionalized patients nationwide to collect statistical information on the “amount, distribution, and effects of illness and disability in the United States” (CDC, 2019). The NHIS has been conducted annually since 1982 and was revised in 1997, with supplemental additions administered starting in 1998. NHIS data is publicly available on the CDC website at [cdc.gov](http://cdc.gov) and is a nationally representative sample of participants. This data set was selected based on the large number of participants and the specific questionnaire items that target topics such as access to care, mental health, insurance type, and epilepsy symptoms. Although data is collected annually, the years 2011 and 2016 ask the same questions related to the above interest areas and capture a particularly useful period of time. The 2011 survey was collected in conjunction with the enactment of the Affordable Health Care Act (ACA) and the 2016 survey was collected after the enactment and implementation of the ACA nationwide, but before any changes that occurred under the Trump administration in 2017.

To collect information, U.S Census Bureau employees conducted personal household interviews to collect survey data. Households are selected randomly from census information and interviewers were trained and monitored by Census Bureau health survey supervisors. Interviewers used laptop computers and input responses into the computer system directly. For child participants, an adult or parent living in the household was randomly selected to provide responses about the child for the child questionnaires; the child may or may not have been present at the time of the interview. All participants in the home who completed the family survey were interviewed at the same time and subsequent interviews with or regarding the

sample adult and the sample child occurred after the initial household and family surveys were completed by all household members present. The NHIS has been used in several published studies evaluating multiple health care variables related to access to care (Akobirshoev et al., 2017; Forsythe et al., 2013; Gonzalez, Goldberstein, Hill & Zuvekas, 2016; McMorrow, Gates, Long, & Kenney, 2016; Nipp, Shui, & Perez, 2018; Palmer et al., 2013; Weissman et al., 2016).

The NHIS includes multiple survey forms that were all collected at one time via a personal interviewer who uses a computer-assisted personal interviewing (CAPI) procedure using a laptop computer. The NHIS has a core questionnaire that remains relatively unchanged between years, and then includes additional questions that vary from year-to-year based on research needs. The Core Questionnaire is divided into four parts: Household, Family, Adult, and Child.

Each year the Household Composition Survey collects demographic information related to the household and is filled out by one adult in the family who is knowledgeable about the family information and is randomly selected from the census data. This person may be different than the individual known as the “sample adult” and described further below. This survey aims to collect demographic information about all individuals living in a particular house.

The Family Core Questionnaire is administered to each family member living in the household who is 17 years of age or older and home at the time of the interview. This survey is intended to collect more individualized information about each person within a family unit, and includes “health status and limitations, injuries, healthcare access and utilization, health insurance, and income and assets” (CDC, 2019). This questionnaire is further organized into a “person file” that associates responses from the family core questionnaire to each individual person.

The Sample Adult Survey is completed by one randomly selected adult in the family and collects additional information about the individual's "health status, health care services, and health behaviors" (CDC, 2019).

The Sample Child Survey is completed by a "knowledgeable adult in the household, typically a parent" on behalf of his or her child (CDC, 2019) and includes similar information as the Sample Adult Survey. In the year 2011 and 2016, this Child survey also included supplemental questions that pertain to mental health status and severity of symptoms and health care access and utilization. For the purposes of this study, questions from the Child Sample Survey were used along with questions from the Family Core Questionnaire that are organized in the "person file" to assess insurance status.

### **Participants**

Children and adolescents ranging in age from 3-16 years old were included in the sample. Those 17 years of age or older were considered for the sample adult survey and were not eligible to participate in the child sample survey. A parent or guardian completed survey responses and only participants whose parents answered "yes" to the question "has had seizures in the past 12 months" were included in this study, as the study population of interest is children who experience seizures and may have epilepsy. Children younger than 3 years of age were not included in this study. These children were excluded to avoid confounding febrile seizures with likely epilepsy, given that participants were not asked about epilepsy diagnosis, but only about having experienced one or more seizures. Febrile seizures are the most common form of seizures in childhood (Okubo & Handa, 2017; Patterson et al., 2013), but children who experience febrile seizures typically do not go on to develop a seizure disorder: Only 4-5% go on to be diagnosed with epilepsy (Leung, et al., 2018). Research indicates that febrile seizures in children often

peak at 18 months of age (Okubo & Handa, 2017), thus excluding children under 3 may help eliminate children from the sample who have experienced seizures but who are unlikely to have or develop epilepsy.

### **Measures**

The parent or guardian of the selected household child provided all responses to study measures. The information collected in the Family Questionnaire includes household annual income and insurance status. This information was collected in a face-to-face interview with the parent and recorded via computer entry by the surveyor. The 2016 measures were used to analyze hypotheses #1, #2, and #3 and the 2011 and 2016 measures were used for hypothesis #4; measures and items for both years are identical.

### ***Seizures***

Parents of child participants were asked, “During the past 12 months has [child’s name] had any of the following conditions?” Response options included, hay fever, any kind of respiratory allergy, any kind of digestive allergy, any kind of skin allergy, frequent or repeated diarrhea or colitis, anemia, three or more ear infections, frequent or severe headaches (including migraines), stuttering or stammering, and seizures. Child participants were included in this study if their parents chose “seizures” in response to this question. Though a history of seizures does not directly indicate a diagnosis of epilepsy, seizures are the main symptom of epilepsy and specialty treatment is still needed for follow up, unless in the case of febrile seizures when the seizure was provoked by fever. The survey did not ask if children had received a diagnosis of epilepsy or if the seizure was provoked by fever.

### ***Health Insurance***

In both the 2011 and 2016 survey, parents were asked, “Next, I’m going to read a list of

ways that treatment and counseling get paid for. Please tell me who pays or paid for [child's name]'s treatment or counseling during the past 6 months.” Response options included: private health insurance (such as insurance that comes with a job), Medicare, Medi-gap, Medicaid, CHIP/SCHIP program, military health care, Indian Health Service, state sponsored health care, other government plan, single service plan, or no coverage of any type.

Those who selected “private health insurance” as the primary source of treatment payment were placed in the private health insurance group. Participants whose parent indicated that treatment was paid for by Medicare, Medi-gap, Medicaid, CHIP/SCHIP program, military health care, Indian Health Service, state sponsored health care and other government plan were placed in the publicly insured group. Those who selected ‘uninsured’ were placed in the uninsured group. Those who selected single service plan were planned to be excluded from the study because the question did not further specify how this plan was paid for (private or public insurer), however, no participants who endorsed seizures selected only this insurance type; therefore, no participants were excluded for this reason. Silver and Stein (2001) used similar definitions in their study, which analyzed related parent-report data for the child survey in the 1994 NHIS. Similarly, Newacheck et al. (1999) also used this item in their study to clarify health insurance status for those who participated in the 1995 NHIS.

### *Access and Utilization of Specialty Care*

In 2011 and 2016, children’s parents were asked 1), “During the past 12 months, was there any time when [child’s name] needed any of the following, but didn't get it because you couldn't afford it?” Response options included: prescription medicines, to see a specialist, follow-up care, mental health care or counseling, dental care, eyeglasses. This question was used

for a similar purpose in the Silver and Stein's (2001) study, which was used as a one-item measure of access to health care.

Participants' parents were also asked 2), "During the past 12 months, has anyone in the family seen or talked to any of the following health care providers about [child]'s health?" Response options included: an optometrist/ophthalmologist/eye doctor, foot doctor, physical therapist/speech therapist/ respiratory therapist/ audiologist/occupational therapist, nurse practitioner/physician assistant/ midwife, a mental health professional such as a psychiatrist/psychologist/psychiatric nurse/clinical social worker, a chiropractor, a medical doctor who specializes in a particular medical disease or problem (other than obstetrician/ gynecologist and other than psychiatrist or ophthalmologist), a general doctor who treats a variety of illnesses (a doctor in general practice, pediatrics, family medicine, or internal medicine).

To create an Access and Utilization of Specialty Care scale for this study, participants received a score of -1 if his or her parent selected 'to see a specialist' in response to question 1) *"During the past 12 months, was there any time when [child's name] needed any of the following but didn't get it because you couldn't afford it?"* and given a 0 otherwise. Endorsing this item indicates that the patient was unable to access specialty care because of cost. The participants received a score of 1 if his or her parent selected 'a medical doctor who specializes in a particular medical disease or problem (other than obstetrician/ gynecologist, psychiatrist or ophthalmologist and other than psychiatrist or ophthalmologist)' in response to question 2) *"During the past 12 months, has anyone in the family seen or talked to any of the following health care providers about [child]'s health?"* Participants were given a 0 if they did not endorse this item.

Scores for these two questions were added to create an Access and Utilization of Specialty Care Measure. Scores on the Access and Utilization of Specialty Care Measure could range from -1 to 1. Higher scores indicate higher level of access to and utilization of specialty care. A similar approach in scale creation was demonstrated in Newacheck et al's (1999) study, which used similar response sets of the 1995 NHIS questionnaire to construct an access to care measure. Spearman-Brown statistic was calculated to assess reliability for the access and use of specialty care scale for both 2011 and 2016. This measure of reliability is appropriate for a two-item ordinal test (Field, 2018). Correlations ranged between  $r(87) = .30, p < .05$  for the year 2011 to  $r(77) = 0.14, p = .24$  for the year 2016. These results indicate a small positive correlation between questions, and this correlation was significant in 2011 but not in 2016. Further, the small correlation is often rejected as it is considered lack of internal consistency reliability, the scale was still used due to lack of alternative questions that target the same information. These same questions were used to create a similar scale in (Thurman et al., 2016) and reliability and validity for this scale was not noted to be a limitation for this study.

### ***Access and Utilization of Mental Health Care***

In 2011 and 2016, participants' parents were asked two questions related to mental health access and utilization, and these questions were used to create a Mental Health Care Access and Utilization scale. Questions to be used in scale construction (along with how response options were coded) are as follows:

For Questions 1) and 2) above (under Access and Utilization of Specialty Care), participants whose parents selected 'mental health care or counseling' in response to Question 1) "*During the past 12 months, was there any time when [child's name] needed any of the following, but didn't get it because you couldn't afford it?*" received a score of -1, because this

indicates they were not able to access the mental health care that was needed. They received a score of 0 for question 1 if they did not select this response.

Participants whose parents selected ‘mental health professional such as a psychiatrist/psychologist/psychiatric nurse/clinical social worker’ in response to question 2) “*During the past 12 months, has anyone in the family seen or talked to any of the following health care providers about [child]’s health?*” received a score of 1, because this indicates that the individual was able to access appropriate mental health care when needed. They received a score of 0 for question 2 if they did not select this response.

Scores for these two questions were added to create an Access and Utilization of Mental Health Care Measure. Scores on the Access and Utilization of Mental Health Care Measure could range from -1 to 1. Higher scores indicate higher level of access to and utilization of mental health care. Measures of specialized services were also created based on similar item responses in Newacheck et al.’s (2000) study, which created an access and utilization measure of specialized services. Spearman-Brown statistic was calculated to assess reliability for 2016 with resulted in a correlation of  $r(77) = 0.21$ ,  $p = .07$ . Spearman-Brown was not calculated for the 2011 sample because all participants scored a 0 for item “can’t afford mental health care” indicating that no participants couldn’t afford mental health care. Although, internal consistency reliability for this scale in this study was not computed, Roll et al. (2013) utilized the same items on the NHIS to measure mental health care use in children and adults in years 1997-2010. They did not provide reliability data for their measure in that study.

### ***Mental Health Symptom Severity***

The Strengths and Difficulties Questionnaire (SDQ) is a behavioral screening questionnaire used to identify emotional and behavioral problems in children. The SDQ has been

found to be a reliable and valid measure for identifying emotional and behavioral problems in children (Goodman 1997; Goodman, 2001). The questionnaire has been used in numerous studies worldwide and has been adapted to several versions. All versions have five scales (emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behavior) and the SDQ-short used in the NHIS Child Sample survey 2016 uses one item from each of the scale categories. The SDQ-short was specifically adapted for the purpose of the NHIS to save time and space in the overall survey (CDC 2019; Ringeisen et al., 2015). The short version has been shown to be a reliable and valid screener of psychiatric disorders in children and has predictive validity with the Schedule for Affective Disorders and Schizophrenia in School-Aged Children (K-SADS); a validated measure of serious mental illness in children (Pastor et al., 2012). All questions on the SDQ have answer choices of not true, sometimes true, and often true. Some items are reverse scored. Table 1 in the Appendix A displays each SDQ question and the associated assigned score. Higher scores on the SDQ-short indicate greater mental health symptom severity and a score of 6 or above is considered severe.

Parents were asked the following questions: “I am going to read a list of items that describe children. For each item, please tell me if it has been: not true, somewhat true, or certainly true for [sample child’s name] during the past 6 months. [Sample child’s name] 1) is generally well behaved/does what is requested in the past 6 months (reverse scored), 2) has many worries/ often seems worried in the past 6 months, 3) is often unhappy/depressed/ tearful, 4) gets along better with adults than children/ youth, 5) has good attention/completes chores and homework (reverse scored). Responses to all questions were scored 0,1,2 so that higher scores indicated higher risk of emotional and behavioral problems. Internal consistency reliability for this measure in this sample was calculated by Cronbach’s alpha statistic and was poor ( $\alpha = 0.54$ ).

Despite the internal consistency being poor in this sample, Kessler et al., 2006 evaluated the 5 question SDQ used in the NHIS and found it to be a reliable and valid measure when including all participants aged 13-17 years. It is possible that the variation in symptom presentation often seen among patients with specialty care needs, resulted in varied responses to SDQ questions, which might mean that internal consistency reliability estimates for the SDQ are a poor indicator of reliability in this sample.

### **Demographic Variables**

Demographic variables that were collected by the interviewers were used to describe the sample. These variables included age, sex, race, and U.S. geographic region. Age was assessed on the child survey by asking: How old is [child's name]? The child's age was recorded in years with answer options that include, less than 1 years old or the number associated with age in years beginning with 1-17 for non-adult household members. Sex was assessed on the child survey using the following question: Is [child's name] male or female? Possible responses to this question were male or female. Race was assessed on the child survey using the following question: Please select [child's name] race: options included White, Black/African American, American Indian (includes Eskimo, Aleut), Chinese, Filipino, Asian Indian, other race, and Multiple race with no primary race selected. Geographic region of household was based on location of survey collection and included categories of Northeast, Midwest, South, and West.

### **Data Analysis**

#### ***Hypothesis #1***

Hypothesis #1 was: In 2016, children who had experienced seizures in the last 12 months and had private health insurance would have greater access to and utilization of specialty care

compared to those who were publicly insured, or uninsured, and those who were uninsured would have less access to and utilization of specialty care compared to those publicly insured.

To test hypothesis #1, a one-way ANOVA was planned to compare insurance group categories on the Access and Utilization of Specialty Care scale. Planned contrasts were designated a priori in order to examine the hypothesized differences between three insurance groups while controlling the family-wise error rate for multiple tests. The first contrast was planned to test whether there was greater access to and utilization of specialty care among those with private insurance compared to the other insurance types. For contrast 1, the privately insured group was therefore given a weight of (+2) and other groups given a weight of (-1) to test this aspect of the first hypothesis. Furthermore, it is likely that those publicly insured have greater access to and utilization of specialty care compared to those uninsured as they do not have barriers that are often common when using insurance coverage and have the means to pay for care. Therefore, the second contrast was planned to test whether those publicly insured had greater access to and utilization of specialty care than the uninsured. For contrast 2, the privately insured group was planned to be given a weight of (0) to remove this group from the contrast, publicly insured was given a weight of (+1) and uninsured group was given a weight of (-1). This scheme for weighing contrasts satisfies the rules for a planned contrast design to control the family-wise error rate and weights were developed using rules for planned contrasts in ANOVA (Field, 2018).

### ***Hypothesis # 2***

Hypothesis #2 was: In 2016, children who had experienced seizures in the last 12 months and had private health insurance would have greater access to and utilization of mental health

care compared to those who were publicly insured, or uninsured, and those who were uninsured would have less access to and utilization of mental health care compared to those with insurance.

To test hypothesis #2, a one-way ANOVA was planned to compare insurance groups on the Access and Utilization of Mental Health Care scale. Planned contrasts were designated a priori in order to examine the hypothesized differences between the three insurance groups while controlling the family-wise error rate for multiple tests. The first contrast was planned to test whether there was greater access to and utilization of mental health care among those with private insurance compared to the other insurance types. For contrast 3, the privately insured group was therefore given a weight of (+2) and other groups given a weight of (-1) to test the aspect of the first hypothesis. Furthermore, it is likely that those publicly insured have greater access to and utilization of mental health care compared to those uninsured. Therefore, the next contrast was planned to test whether those publicly insured had greater access to and utilization of specialty care than the uninsured participants. Thus, for contrast 4, the privately insured group was planned to be given a weight of (0) to remove this group from the contrast, the publicly insured group was planned to be given a weight of (+1) and the uninsured group was planned to be given a weight of (-1), to test this aspect of the hypothesis. This scheme for weighing contrasts satisfies the rules for a planned contrast design to control the family-wise error rate, and weights were developed using rules for planned contrasts in ANOVA (Field, 2018).

### ***Hypothesis #3***

Hypothesis #3 was: In 2016, children who have experienced seizures and who reported more severe mental health symptoms would have less access to and utilization of mental health care. To test this hypothesis, a Pearson's correlation was performed correlating the SDQ total scale and the access to mental health care scale.

***Hypothesis #4***

Hypothesis #4 was: The disparity in access to and utilization of mental health care among participants who had private vs. public health insurance would be larger in 2011 than in 2016. To test this hypothesis, a two-way ANOVA factorial design was performed, with two independent variables, year of survey and health insurance type, and one dependent variable, the access to and utilization of mental health care scale.

**Ethical Issues**

A brochure with information about what the NHIS is, where the information is stored, what the information is used for, and why the survey is conducted was given to each participant. The survey began if the participant consents after this information is given and explained. The U.S Census Bureau trained surveyors in basic interviewing skills and procedures. It is possible that answering questions on the NHIS survey regarding mental health could be distressing for some individuals and a potential risk of completing the interview. However, participants of this present study were not interviewed directly, and participants' parents were interviewed instead. In addition, interviewers worked directly with survey respondents; therefore, those collecting responses were aware of identifying information of participants when information was originally collected. However, there were not additional risks of this current research beyond that of the original survey. There was no deception involved in this study. Participants consented to the public use of non-identifiable information when completing the survey and were informed they would not be notified each time the data are used for research. However, participants are informed that if continued research is conducted and citations are made available, citations will be linked to the data and published on the CDC website for survey years and participants may find any additional information on that website.

***Confidentiality***

Survey participation and response to questionnaire items were confidential. All data used in this study are publicly available for download at [wwwn.cdc.gov/nchs/nhanes/default.aspx](http://wwwn.cdc.gov/nchs/nhanes/default.aspx). No identifying information is included in the publicly available data file, and it would not be possible for this researcher to identify or contact any family, parent, or child who provided information for this study. Participants were given a brochure explaining the confidentiality of the survey, which can be found in Appendix B. The CDC reports that confidentiality is assumed under section 308(d) of the Public Health Service Act which states, in sum, that no identifiable information will be released to a researcher outside of the CDC unless consent is given from the participant to release their identifiable information (CDC, 2019).

***Information and Debriefing***

Participants who provided information for the National Health Interview Surveys in years 2011 and 2016 were provided a brochure with full disclosure of use of information. Participants were given direction to find subsequent research related to this survey and more information regarding the use of data by going to [cdc.gov/nchs](http://cdc.gov/nchs) and finding the year of their participation. Participants were also given a contact number and email for a confidentiality officer with the CDC if participants had additional questions after their participation in the survey. Participants consented to complete the survey with the knowledge that the data would be publicly available for future, undescribed research and are not informed that data are being used each time it is downloaded.

***Retention of Data***

Data for this study are publicly available. SPSS syntax and output files related to this study will be retained indefinitely.

*Permissions*

The SDQ is copyrighted by Dr. Robert Goodman, Institute of Psychiatry, London, England (Goodman, 1997, 1999) and was used with his permission for the NHIS. Written permission was not needed for the purpose of this study as the data are publicly available.

## Chapter 4 Results

### Descriptive Information about the Samples

The 2011 sample included 87 participants who have experienced seizures, ranging in age from 3 to 17 years old, with the mean age of 9 years old. Nineteen participants were under the age of 5 years old. In this sample, 38 participants were identified as male, and 49 participants as female. Most participants were from the southern and western United States: 31% from the West region, 39% from the South region, 17% from the Midwest, 13% from the Northeast. In terms of race, 65.5% of participants were White, 24.1% Black, 3.4% Native American, 3.4% Asian Indian, 1.1% Filipino, 1.1% Other Asian, and 1.1% did not identify their race. Table 4.1 displays complete breakdown of insurance type by race for years 2011 and 2016.

The 2016 sample included 77 participants who have experienced seizures, ranging in age from 3 to 17 years old, with the mean age of 9 years old. Eleven participants were under the age of 5 years. In 2016, 45 participants were identified as male, and 32 participants were identified as female. Again, participants were predominantly from the South and West: 33% were from the West, 35% from the South, 16% from the Midwest, and 17% from the Northeastern United States. In terms of race, 76.6% of participants were White, 18.2% Black, 1.2% Native American, 1.3% Asian Indian, and 2.6% multiple races.

Table 4.1 Race by Type of Insurance Combined years 2011 and 2016

Race	Uninsured N (%)	Publicly Insured N (%)	Privately Insured N (%)	Total 164
White	22 (23%)	23 (24%)	50 (53%)	95
Black	6 (18%)	16 (48%)	11 (33%)	33
Indian American	1 (25%)	2 (50%)	1 (25%)	4
Asian Indian	1 (<1%)	8 (67%)	3 (25%)	12

Filipino	0 (0%)	0 (0%)	1 (100%)	1
Other Race	1 (<1%)	6 (50%)	5 (42%)	12
Multiple Races	1 (25%)	0 (0%)	3 (75%)	4
Did not answer				3

In general, the number of participants who endorsed having seizures was somewhat low but within range of what would be expected for the overall sample sizes of 12,858 and 11,107 for the years 2011 and 2016 respectively. Lower endorsement of pediatric seizures is likely because the majority of the sample was adults, not children. Research demonstrates between a .5% - 1% prevalence rate of epilepsy among children in the U.S and other countries; therefore, it would be expected that approximately 55-129 child participants would endorse at least some level of seizure activity for each year, even if participants did not have a diagnosis of epilepsy. Endorsement of seizures was within range of this estimate; 87 participants in 2011 and 77 participants in 2016 endorsed seizures in the last 12 months (Aaverg et al., 2017; Fiest et al., 2017).

Table 4.2 displays insurance type and access and use of mental health care for participants who experienced seizures in 2011. As displayed, of the 87 participants who endorsed seizures in the 2011 sample, 29% of participants were uninsured, 29% had public insurance and 31% participants were privately insured. Scores on the mental health care scale ranged from 0 to 1 ( $M = 0.25$ ,  $SD = 0.44$ ), reflecting that all participants denied that cost was a barrier to their access. 25% of participants reported accessing mental health care; among that group, 27% were uninsured, 36% were publicly insured, and 36% were privately insured. Of the 65 participants who did not use mental health, 29% were uninsured, 26% were publicly insured, and 45% were privately insured.

Table 4.2.

## Insurance Type and Access and Use of Mental Health Care - 2011

	Total	Uninsured	Publicly Insured	Privately Insured
		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
	87	25 (29)	25 (29)	37 (43)
Accessed and used mental health care ( <i>cost not a barrier</i> )	22 (25)	6 (27)	8 (36)	8 (36)
No use of mental health care ( <i>cost not a barrier</i> )	65 (75)	19 (29)	17 (26)	29 (45)

Table 4.3 displays insurance type and use and access (i.e., cost as a barrier) of mental health care who experienced seizures in 2016. As displayed, of the 77 participants who endorsed seizures in the 2016 sample, 22% of participants were uninsured, 29% had public insurance and 49% of participants were privately insured. Mental health access and use scores ranged from -1 to +1 ( $M = 0.27$ ,  $SD = 0.48$ ): 29% of participants reported receiving care and that cost was not a barrier, 65% of participants did not access mental health care and cost was not a barrier, 4% of participants responded that they accessed mental health care, but cost was a barrier. Finally, 1% of participants reported not receiving mental health care because cost was a barrier to accessing care.

Table 4.3.

## Access and Use of Mental Health Care by Insurance Type - 2016

	Total	Uninsured	Publicly Insured	Privately Insured
		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
	77	17 (22)	22 (29)	38 (49)

Used mental health care and cost was not a barrier.	22 (29)	6 (27)	8 (36)	8 (36)
No use of mental health care and cost not a barrier.	50 (65)	9 (18)	13 (26)	28 (56)
Used mental health care and cost was a barrier.	3 (4)	1 (33)	0	2 (67)
No use of mental health care and cost was a barrier.	1 (1)	1 (100)	0	0

Regarding specialty care, table 4.4 displays access and use of specialty care by insurance type, scores ranged from 0 to 1 ( $M = 0.52$ ,  $SD = 0.50$ ). 57% reported accessing specialty care and that cost was not a barrier in accessing this care. 42% of participants did not use specialty care and reported that cost was not a barrier to accessing this care, and 5% indicated that they accessed specialty care, but cost was a barrier.

Table 4.4.

Access and Use of Specialty Care by Insurance Type - 2016

	Total	Uninsured	Publicly Insured	Privately Insured
		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
	77	17 (22)	22 (29)	38 (49)
Used specialty care and cost was not a barrier.	44 (57)	13 (30)	12 (27)	19 (43)
Use of specialty care and cost was a barrier.	4 (5)	1 (25)	1 (25)	2 (50)
No use of specialty care and cost was not a barrier.	32 (42)	4 (13)	9 (28)	19 (59)

In 2016, of the 77 total participants, 66 participants completed the SDQ questionnaire. Of the 66 respondents, scores ranged from 0 to 8 ( $M = 3.21$ ,  $SD = 2.45$ ). One-quarter of participants endorsed moderate to severe mental health symptoms, as indicated by a SDQ score of 5 or

higher. Of the group with severe mental health symptoms, 29% of the participants were uninsured, 18% of participants were publicly insured, and 53% were privately insured.

### **Insurance Type and Access to and Utilization of Specialty Care**

Hypothesis 1 sought to test if those who had experienced seizures in the last 12 months and had private health insurance had greater access to and utilization of specialty care compared to those who were publicly insured or uninsured in 2016. It was further hypothesized that those who were uninsured would have less access to and utilization of specialty care compared to those who were publicly insured.

To test hypothesis #1, a one-way ANOVA was planned. However, there was a restriction of range in participant responses to the Access and Utilization of Specialty Care scale such that all participants received a total score on this scale of either 0 or 1. Since there was no range of scores on the measure, an ANOVA could not be performed. A score of 0 indicates either that participants did not utilize care and cost was not a barrier to accessing care, or that they utilized care, but the cost was also a barrier to receiving appropriate care at some point in the last 12 months. A score of 1 indicates that they utilized care and cost was not a barrier to accessing this care. No participants scored a -1 which indicates cost was not a barrier to accessing mental health care for participants that did not utilize mental health care.

Two chi-square analyses were performed to test Hypothesis 1, by comparing the publicly insured, privately insured, and uninsured groups (the independent variable) against the two single questions that were used to measure access (cost) and use. First, a chi square was performed comparing insurance type against whether the family had seen a medical specialist. A second chi-square analysis was performed comparing insurance type against whether the child needed care but did not obtain it because of cost.

For the first chi-square, all expected frequencies were greater than 5, meeting the assumptions for use of chi square. There was no significant association between the type of insurance and use of specialty care  $\chi^2(2) = 3.45, p = .18$ . Cramer's V was used to measure how strongly the two categorical variables are associated and demonstrated a medium-sized effect ( $V = 0.21$ ). For the second analysis, expected frequencies were not all above 5, and therefore chi square could not be performed; therefore, Fisher's exact test was used to test the association between insurance and ability to afford specialty care. There was no significant association between the type of insurance and ability to afford specialty care  $p = 1$ .

Further, when observing the total number of participants in this sample, a larger proportion of uninsured children accessed and used specialty care than did privately or publicly insured children. In fact, privately insured children's parents most frequently reported no use or experiencing barriers to specialty care for their child. Therefore, hypothesis 1 was not supported.

### **Insurance Type and Access to and Utilization of Mental Health Care**

Hypothesis 2 tested if those who had experienced seizures in the last 12 months and had private health insurance would have greater access to and utilization of mental health care compared to those who are publicly insured, or uninsured for the year 2016. Further, it was hypothesized that those who were uninsured would have less access to and utilization of mental health care compared to those privately insured or publicly insured.

To test hypothesis #2 a one-way ANOVA was performed with a Welch's-F correction. There was no statistically significant difference across the three insurance categories in mental health care access or utilization, ( $N = 77$ ),  $F(2, 34.42) = .77, p = .47$ . Thus, since there was no difference observed overall among the groups, planned contrasts comparing the differences between groups were not performed. The effect size for this test was small,  $\eta^2 = 0.02$ , and the

results were non-significant. Looking at the mean scores in this sample, those publicly insured had the highest access to and utilization of mental health care ( $n = 22$ ,  $M = .36$ ,  $SD = .49$ ), those uninsured had the second-highest access to and utilization of mental health care ( $n = 17$ ,  $M = .29$ ,  $SD = .58$ ), and privately insured participants accessed and utilized mental health care the least ( $n = 38$ ,  $M = .21$ ,  $SD = .41$ ). This pattern of means is contrary to the hypothesis, suggesting that lack of power to detect an effect does not explain these findings.

### **Mental Health Symptom Severity and Access to and Use of Care**

The third hypothesis stated that participants with more severe mental health symptoms would have less access to and utilization of mental health care in 2016. To test this hypothesis, a Pearson's correlation was performed correlating the SDQ total scale score and the Access and Utilization of Mental Health Care scale score. 10 participants did not complete the SDQ ( $n = 67$  for this analysis), and SDQ scores ranged from 0 to 8 ( $M = 3.2$ ,  $SD = 2.45$ ). There was a significant relationship between the severity of symptoms and access to and utilization of mental health care,  $r = 0.35$ ,  $p < .001$ . However, these results were contrary to the hypothesis: those with more severe symptoms had more access to and utilization of mental health care.

### **Changes Over Time in Access to Care by Insurance Type**

The fourth hypothesis in this study stated that the hypothesized disparity in access to and utilization of mental health care among participants who had private vs. public health insurance would be larger in 2011 than in 2016. To test this hypothesis, a two-way ANOVA factorial design was used, with two independent variables, year of survey and health insurance type, and one dependent variable, the access to and utilization of mental health care scale. Consistent with the 2016 results, the main effect for insurance type was not statistically significant,  $F(2,156) = 0.84$ ,  $p = 0.43$ , comparing uninsured ( $M = 0.26$ ,  $SD = 0.50$ ), publicly insured ( $M = 0.33$ ,  $SD =$

0.47), and privately insured ( $M = 0.22$ ,  $SD = 0.41$ ) groups. The main effect for year of survey was also non-significant,  $F(1, 156) = 0.26$ ,  $p = 0.61$ , comparing 2011 ( $N = 85$ ,  $M = .25$ ,  $SD = .43$ ), to 2016 ( $N = 77$ ,  $M = .27$ ,  $SD = .48$ ), indicating no significant difference overall between 2011 and 2016 in access to and utilization of mental health care. Finally, the interaction was also not significant  $F(2,156) = 0.14$ ,  $p = 0.87$ . There is disparity across years which is contrary to the hypothesis. Figure 4.1 below depicts estimated marginal mean scores in access and utilization of mental health by insurance type and year.

## Chapter 5: Discussion

Children who have seizures are at risk for epilepsy and those with epilepsy often go on to have lifelong challenges that require specialized care throughout the lifespan. Specialized care, including mental health care, is most effective in altering disease course when provided in childhood (Camfield & Camfield, 2007; Ivanova et al., 2010). More specifically, treatment of mental health challenges directly influences the treatment of seizure symptoms and vice versa (Jones 2007), but specialty care and mental health treatment are often interrupted by multiple barriers; one of which is insurance type (Baca et al., 2013; Halpern et al., 2011; Schiltz et al., 2013; Sorin et al., 2019).

Broader research examining large populations of patients with chronic health care needs (both children and adults) identifies disparities between insurance types in access and use of specialty care and mental health (Callaghan et al., 2019; Halpern et al., 2011; Thurman et al., 2016). Patients with chronic conditions are often uninsured or publicly insured (Verlenden et al., 2021; Wilper et al., 2008) and experience more barriers when attempting to access specialty care compared to non-specialty forms of health care (e.g., primary care or emergency room visits; Mayer et al., 2004). Additionally, patients with greater health challenges (increase symptoms severity) often have more difficulty accessing care, despite their need (Ott et al., 2003) and mental health severity specifically has been shown to correlate with lack of access and use of mental health care (Priester et al., 2016). There are many barriers to accessing care, but unmet specialty care needs are often correlated with being uninsured or publicly insured, especially for those with Medicaid/CHIP specifically (Bisgaire & Rhodes, 2011; Halpern, Renaud, & Vickery, 2011; Mayer et al. 2004). In general, those with private health insurance often receive more

comprehensive care and overall have better access and utilization of specialty care services (Baca et al., 2013; Halpern et al., 2011; McClelland et al., 2007; Schiltz et al., 2013).

Specific to this present study, research conducted with adult epilepsy populations demonstrates general trends that indicate participants do not receive needed specialty care and mental health care (Thurman et al., 2016). Previous research has not examined access and use among different insurance types specifically, but consistently notes that those with private health insurance have less barriers to care (Sorin et al., 2019; Thurman et al., 2016). Very little research has been conducted around insurance and access and utilization of specialty care and mental health care for epilepsy patients in general, and only recently has a study examined insurance as a barrier in an adult epilepsy sample population (Szaflarski et al., 2020). Among the research accessible, no studies have examined pediatric populations specifically (Szaflarski et al., 2020; Thurman et al., 2016). Therefore, the aims of this study are important in providing a closer look into how insurance type and symptom severity may impact access and use of specialty and mental health care for pediatric patients with seizures, which no study has done before.

Additionally, this study aimed to examine the relationship between insurance type and access to and utilization of mental health care for two specific time periods (before and after the enactment of the ACA), with the hope that this information could aid policy decisions related to health care coverage. The two specific time points selected for this study were 2011 and 2016, due to the insurance policy changes with the enactment of the ACA, which aimed to make insurance access more available and affordable (Dorner et al., 2015). Data from 2016 was used for the first three hypotheses independently as it provides a unique timepoint after the enactment of the ACA and prior to any health care changes initiated in 2017. These data were compared to

2011 data to compare any alterations over time in the context of policy changes regarding insurance.

Research has been mixed in the effectiveness of reducing barriers to specialty care for those who do not have private insurance since the enactment of the ACA (Doener et al., 2015; Monaghan, 2014; Timbie et al., 2019). Therefore, this present study examined if any changes occurred in access and use of care in this specific subset of a child sample.

### **Lack of Relationship Between Insurance and Access to Care**

For this study, it was predicted that participants with private health insurance in 2016 would have greater access to and utilization of specialty care and mental health care compared to those publicly insured or uninsured, and that those publicly insured would have greater access to and use than those uninsured.

Despite previous research suggesting that insurance type affects access to and utilization of specialty care, this study did not find statistically significant differences in access and utilization of specialty neurology care among participant children with seizures who had various insurance types. There were also no statistically significant changes in access and utilization of mental health care between 2011 and 2016, either overall or by children's insurance type.

To the extent that there were any mean differences even solely among the participants in this sample, the pattern of results was contrary to the original hypothesis, suggesting that it was not sample size or lack of power to detect an effect that explains these null findings.

### ***Specialty Care***

Results of this study present a contrary result to what has been previously seen in the literature regarding insurance and access and use of specialty care among adults, and adults with epilepsy. For example, Szaflarki et al's., 2020 found ongoing challenges for uninsured adult

patients with epilepsy to have appropriate access to health care. Their study also used the NHIS as their sample population and the odds of seeing a neurology specialist for adult epilepsy patients were far lower for those uninsured than those who were publicly or privately insured. That study also found no significant difference between those publicly insured or privately insured in access to care. A similar trend of disparities facing uninsured participants, and a closing gap between publicly and privately insured patients, is demonstrated across other research that examines non-epileptic adult samples (Seo et al., 2019).

It is possible that children who are uninsured with chronic health conditions, such as epilepsy, fare better than adults. Perhaps they are seen at community health centers or academic institutions that have lower or no cost to care due to other means of funding (e.g., federal grants and academic grants). However, in this sample, it is unclear how the participants accessed specialty care because the means to access was not assessed. Further, it is also possible that parents can advocate for children who have had seizures in a way that adults with epilepsy are not able to advocate for themselves.

### ***Mental Health Care***

In the present study, there were no significant differences between insurance types in access to and use of mental health care. Some recent studies, not specific to epilepsy, find that public insurance is providing better access to mental health care as compared to private insurance in some states (McConnell et al., 2020). There has been an overall increase in reimbursement rates for providers with some public insurances (i.e., Medicaid) and an increase in the number of providers who take public insurance (McConnell et al., 2020). ). Despite policy changes in attempts to improve access to mental health care, recent reports demonstrate that in general (not epilepsy specific) private insurance plans that did not include mental health coverage for children

has increased (Reinert, Fritze, & Nguyen, 2021). Thus, it is possible that among children with seizures, the historical advantage private insurance offered in access to mental health care may be coming to an end as health care costs increase even for those privately insured.

An alternative explanation is that those who are publicly insured or uninsured are more likely to be in a lower SES compared to privately insured patients. Low SES is associated with having more severe mental health challenges, due to the increased stressors that often accompany low SES (Reiss 2013). Therefore, those who are privately insured in this sample may simply not have needed to access mental health care as much as those who lacked resources and therefore held public or no insurance. For example, those with higher SES often have access to other health care options, ability to adhere to strict diets and medication regimens to aid in treatment, and decreased life stressors which aid in healthy mental status and quality of life without need for formal specialty care.

It is unclear whether the lack of significant findings in this study reflects a genuine reduction in health care access disparities for publicly insured and uninsured pediatric seizure patients. If so, it is possible that insurance type may not be as large of a barrier for mental health and specialty care among children with seizures, and that other health care barriers, such as stigma, assumed inefficacy of mental health for epilepsy, and challenges finding a mental health provider knowledgeable about co-occurring disabilities are of equal or greater importance (Smith et al., 2007). Insurance type is only one assumed barrier among a myriad of interacting and co-occurring factors for these patients.

### **Insurance Type and Access to and Use of Care at Two Time Points**

It was predicted that the disparity in access to and utilization of mental health care among participants who had private vs. public health insurance would be larger in 2011 than in 2016.

The hypothesis investigated here was based on the presumption of more access to mental health care with the Mental Health Parity Act of 2008 and increased insurance access with the Affordable Care Act of 2010, which intended to broaden access and reduce cost barriers to health care. Research has suggested that mental health care access has improved for some populations with specialized mental health care needs (e.g., children with Autism) after the enactment of the ACA and the Mental Health Parity Act (Stuart et al., 2017). However, the present study found no significant difference in access and utilization of mental health care comparing the year 2011 to 2016. Recent research has shown a similar pattern and that those with public insurance have appropriate access to mental health care, despite continued disparities in general health care and other specialty care fields (McConnel et al., 2020). It appears that the gap in access to care between those privately insured and publicly insured may be narrowing for pediatric patients with specialty care needs. The results of this present study suggest that the implementation of the ACA did not dramatically change access and utilization of mental health care for U.S. kids with seizures. These results support increased parity enforcement and additional policy changes. Changes to reduce barriers to care will help ensure that children with epilepsy care are connected to mental health providers that offer evidence-based treatment and are educated in co-occurring symptoms and disorders.

Additionally, the lack in change of access and use of mental health care may be an indication of continued stigma around both epilepsy and mental health. It is possible that in 2011 and in 2016 stigma surrounding mental health disorders and care remained stable resulting in lack of access and use. Since 2016 there have been continued efforts to reduce stigma around mental health and neurological disorders. Therefore, it is possible that attempts to access or use

mental health may increase over time with decreased social stigma. This variable may be an area of future research.

### **Symptom Severity and Access to and Use of Mental Health Care**

It was predicted that participants with more severe mental health symptoms would have less access to and utilization of mental health care, because in adult populations with epilepsy those with more severe mental health symptoms had less access and use of mental health care (Thurman et al., 2016). However, most adults with severe symptoms in Thurman et al. (2016) were uninsured and had more severe epilepsy symptoms. Further, in a child sample, children with more severe behavioral difficulties, as reported on a symptom rating scale, were less likely to access mental health care (Ott et al., 2003).

In this sample, one quarter of participants endorsed moderate to severe mental health symptoms, which is consistent with prevalence rates among children with epilepsy reported in other studies (LaGrant et al., 2020). Contrary to hypotheses, those with more severe symptoms had significantly more access and utilization of mental health care than those with less severe symptoms. It appears that in this sample, the children with more severe mental health symptoms were able to access mental health care appropriately and, in general, cost was not a barrier. This result is surprising and encouraging because there is often a connection between lack of insurance coverage and more severe mental health challenges in patients with epilepsy which often results in less access to care (LaGrant et al., 2020). However, in this sample it appears that despite insurance coverage, those with more severe mental health challenges had more access and utilization of mental health care.

A possible explanation as to why children with more severe mental health challenges were able to access and use mental health care is that children are often aided by their parents in

navigating health care, unlike adult epilepsy patients (e.g., driving, holding a job). Often pediatric patients with chronic disorders are more routinely seen, which provides more opportunity for mental health symptom screening and advocacy for additional care (Geerlings et al., 2015; Geerlings, 2016). Further, research suggests that adults with more severe depressive symptoms have difficulty utilizing care regardless of severe medical comorbidity status. This is likely due to feelings of hopelessness, fatigue, and difficulty demonstrating appropriate help seeking behaviors (Weissman et al., 2016). Therefore, symptom severity may not negatively impact access to treatment for pediatric patients as much as it does adult patients who are managing their own health care while mentally impaired.

Behavioral presentation of mental health challenges may be another reason as to why participants with severe symptoms in this sample were able to access care. Those with the most severe challenges likely have accompanying behavioral challenges which elevate the perceived need for mental health care. However, research suggests that children with epilepsy often have subclinical levels of mood problems leaving them at risk for additional challenges compared to their peers (Vega et al., 2011). Therefore, it is possible that those with severe symptom presentation were accessing and utilizing care because these symptoms troubled their families or caused impairment with family life or school. Comparatively, it may be the case that in adult populations severe behavioral challenges are misinterpreted as symptom presentation of epilepsy and not as separate mental health disorders that can be simultaneously treated.

It is encouraging that those with moderate to severe symptoms reported access and use of mental health care. This may indicate the beginning of appropriate level of care. However, receiving mental health care does not mean that the provider was equipped or competent in

treating co-occurring disorders with epilepsy, and further investigation regarding the type, adequacy and level of mental health care is needed.

### **Other Barriers to Access and Use of Specialty Care and Mental Health Care**

The results of this study provide possible evidence that other social determinants are equal or greater barriers to access and use of specialty care and mental health care beyond insurance type. Previous research has indicated that low income, race, geographic region, lack of parental education, language proficiency, and parental job type, are possible barriers to accessing and adhering to care (Baca et al., 2013; Bailey, West, Agarwal & Kumar, 2021; Begley et al., 2009; Burneo et al., 2009; Halpern et al., 2011; Mayer et al., 2004; McClelland et al., 2007; McConnell et al., 2020; Ott et al., 2003; Thomas & Nair, 2011). One reason for the robust association between insurance type and access to care in previous studies may be that insurance type is serving as a marker of other factors related to socioeconomic status. These other socioeconomic barriers may be the actual cause of the barrier to care or that may contribute to additional barriers in accessing care. For example, private insurance is often a plan paid for in part or whole by an employer; therefore, having private insurance likely indicates that caretakers of child participants have a place of employment. Further, in 2016, Americans were mandated by law to have health insurance if they could afford it and were subject to paying a fine or penalty if a plan was not selected after the open enrollment period (Healthcare.gov). Therefore, participants uninsured in this sample were likely facing severe financial hardship in addition to lack of health insurance coverage, which likely adds to the complex barriers preventing access and use of mental health care.

In this sample, for both 2011 and 2016, the majority of participants who identified as White were privately insured. Most non-White participants had public insurance or were

uninsured. Table 4.1 provides a complete breakdown of race by insurance type. These patterns demonstrate the previously noted factors that may also contribute to access and use of care.

### ***Specialty Care***

Despite lack of significant results, there was some indication in this sample of barriers to accessing appropriate specialty care regardless of insurance type. In this study, only 57% of participants in 2011 and 49% of participants in 2016 reported access and use of specialty care. The reality that roughly half of participants accessed specialty care within the same year of their seizure is concerning. It is possible that some of these participants had febrile seizures that did not require specialty care follow up; however, that likely accounts for only a small portion of those who did not utilize care. This suggests that specialty care utilization is low among this population despite the need for specialized care. It is possible that other barriers may be interrupting care to a greater degree based on the low utilization across all insurance types (Bailey et al., 2020).

### ***Mental Health Care***

For this sample, 75% of participants in 2011 and 71% of participants in 2016 did not access or use mental health care, indicating other factors are creating obstacles in accessing care. Accessing and utilizing mental health services comes with additional barriers such as stigma, assumed inefficacy of mental health for epilepsy, and challenges finding a mental health provider knowledgeable about co-occurring disabilities (Smith et al., 2007). One recent study suggests that the stigma of an epilepsy diagnosis and a mental health diagnosis (double-stigma) results in patients not disclosing mental health status fully to their medical providers. When patients do disclose mental health concerns, primary care providers are often not equipped to educate patients about mental health care and do not properly screen for symptoms (Mula & Kaufman,

2020). The lack of access and use of mental health care among this population is somewhat shocking considering the rate at which mental health disorders co-occur with seizure presentation (and the common rate of moderate to severe mental health symptoms in this sample). Research is also clear in demonstrating that those with epilepsy who participate in mental health treatments have better seizure outcomes and prognosis (Coppola et al., 2019; Tang et al., 2004). A possible explanation to lack of use of both specialty care and mental health care is that primary care may be filling the gap to meet these needs, which consequently reduces the perceived need for specialty care (Kyanko et al., 2022).

### **Limitations**

A primary limitation of this study is that the sample population includes those who have experienced seizures and not those who have received a diagnosis of epilepsy. Approximately 10% of the U.S population will experience at least one seizure in their lifetime but only approximately 5-10% of those people (children and adults) will go on to be diagnosed with epilepsy (Aaverg et al., 2017; Angus-Leppan, 2014; WHO, 2019). Further, despite the very large number of NHIS participants overall (both children and adult), only 87 participants from the 2011 sample and 77 participants from the 2016 sample endorsed experiencing seizures, resulting in small sample sizes. Therefore, this sample likely captured a very small number of children who may go on to have a diagnosis of epilepsy; most of the participants in this study may not need specialty care or higher levels of mental health care due to seizures. The small sample size is likely a result of the fact that the NHIS participants were mostly adults, and as a household survey, the NHIS likely does not capture the most vulnerable children with mental health needs, resulting in an underestimate. The survey only addresses one select child in the household and

despite surveying a large number of households, the select child may not have been the child with specialty health care needs.

Examining a pediatric population adds an additional layer of complexity because their access and use of care is dependent on parental engagement, knowledge, and support. Therefore, a limitation of this study is that it cannot remove the interaction of parental involvement and is dependent on family SES status, education level, and reporting of symptoms and care. For example, mental health symptom severity for these child participants was reported by their parents. Parental questionnaires as assessment of pediatric mental health symptoms often result in under-reporting of positive symptoms and over-reporting of negative symptoms (Berg, et al., 2017), which is an additional consideration in the interpretation of the results of this study.

Though the NHIS is a population-based study, the means of data collection requires that parents or guardians of the participant child be home at the time of the interview. It can be assumed that those with busier lives, inability to have traditional work hours, and feel unsafe about answering the door for a stranger may filter a portion of participants who may have additional hardships in accessing care. These factors may be an area of future research in examining the generalizability of results using NHIS data.

A possible reason for low access and use of care in this present sample may be as simple as parents under-reporting specialty care use. It is possible that the vague wording of the survey description may have resulted in underreporting. Research demonstrates that the wording on the NHIS specifically resulted in under-reporting by caretakers of unmet health care needs for their children (White et al., 2022). Further, the cohorts at the two time points are of different samples (i.e., not the same people completed the survey both times), therefore the lack of change observed may be due to number of confounding variables such as change in political

leaders/policy change, economy change, perception of health care, different pools of people being selected, different interviewers prompting the survey, and population knowledge of aspects of mental health.

A primary limitation of this present study is the lack of internal consistency reliability for the access and use scales for specialty care and mental health care within this sample. Previous studies that have used these measures for access and use (Nipp et al., 2016; Thurman et al., 2016) have not reported internal consistency reliability for them; future research should evaluate internal consistency reliability for these measures, and also should assess whether internal consistency is a useful metric of reliability for these brief scales. The mental health symptom severity scale (SDQ) has shown internal consistency reliability in other samples and previous research but had poor internal consistency reliability in this sample. This may have been because of small sample sizes, greater variability in responding among children and parents facing medical concerns such as seizures, or other factors. However, the limited internal consistency reliability of these scales requires caution when generalizing these results.

A widely criticized aspect of the NHIS is the breakdown of racial descriptive categories and lack of ethnic specifiers. Asian categories were divided into “other Asian” and “Indian Asian” thereby generalizing a wide variety of Asian ethnicities. There is no category option for those who identify as Hispanic or Latinx ethnicities and are thereby forced to select racial categories only. The lack of specificity in racial and ethnic descriptors often limits generalizability and misrepresents some populations systematic hardships, especially related to SES factors such as insurance type. This limitation in it of itself reflects a larger problem highlighting the lack of diversity consideration when constructing what is intended to be a nationally representative sample. Future research, and possibly that which includes the NHIS,

should examine racial and ethnic categories for accuracy and inclusion of diverse and intersecting identities.

### **Clinical Implications**

This present study examined a unique subset of the NHIS sample population and is the only study to directly evaluate the impact of insurance type on specialty care and mental health care for a pediatric sample who have experienced seizures. There are many studies that explore specialty care and possible barriers, but this study aimed to look specifically at insurance type to explore the strength of this possible barrier. The results of this study highlight the reality that few patients use specialty care or mental health care regardless of insurance type. Lack of care in childhood could possibly begin a trajectory of lack of appropriate treatment throughout the lifespan. This may explain a similar pattern of results seen in literature with adult samples (Thurman et al., 2016). It could be hypothesized that if a patient is not well connected and consistent with services, they are likely to fall through the cracks at some point throughout their lifespan possibly explaining the harsh transition from pediatric to adult care (Geerlings et al., 2015). Gaps in care regardless of insurance, indicates that more work is to be done in educating providers and caretakers of children with seizures on appropriate follow up care.

Having one seizure may or may not result in lifelong implications (depending on seizure severity); however, having multiple seizures indicates a high level of specialty care need. Research presented above strongly states that speedy access to quality care significantly impacts the trajectory of the disorder. The underutilization of specialty care within the same year of even one seizure is concerning. It is extremely important to continue evaluating barriers to specialty care because those with unmet health care needs go on to have poor treatment outcomes and higher rates of mental health disorders (LaGrant et al., 2020). This present study is sounding the

alarm to observe other barriers that may be more easily and immediately changeable than enacting changes to insurance policy. The research on broadening access to and use of care in epilepsy patients is limited, but proposed suggestions include parental education programs, increasing provider education, streamlining diagnostic tools, enacting anti-discrimination policies, increasing reimbursement rates for modes of alternative care (e.g., telehealth), implementing patient-centered epilepsy care models, and exempting low-income families of some costs (ILAE, 2020; Samanta et al., 2021). Future research may evaluate the implementation of these alternate approaches and if care improved, regardless of insurance type.

In addition to no significant differences in insurance type and access and use of specialty care or mental health care, there also were no significant changes in access and use of mental health care at two different time points. This suggests that insurance may not be the leading barrier in access and use of care for this population, encouraging continued research of other barriers to care. For example, other research suggests that limited provider knowledge of treatment options for this disorder is a primary barrier in appropriate access and use of treatment (Beatty et al., 2020; Cotterman-Hart, 2010; Mula et al., 2020; Smith et al., 2007). However, this study did not examine provider knowledge, therefore continued research of this area may be helpful in developing processes and programs to aid providers in further understanding co-occurring disorders in patients with seizures. Utilizing a large sample population from a survey targeted at those with special needs (and not only those with one seizure) may also be a more effective way to examine the relationship between provider knowledge and access to care (for example National Survey of Children with Specialty Care Needs; CDC 2022).

This present study demonstrated that those with more severe mental health care needs were able to access and use mental health care more than those with less mental health

symptoms. This likely indicates that those with the most visible needs are gaining access to care. Though this is a positive sign, it does reinforce that there are varied levels of mental health access and use among those with epilepsy. Even mild symptoms should be considered important and those who have experienced seizures may need supportive mental health care at varied points in their treatment journey. As mentioned, providers may not be knowledgeable of co-occurring disorders for epilepsy patients. Therefore, it is possible that some mental health symptoms are misattributed as symptoms of epilepsy and go untreated due to limited knowledge of the provider. Therefore, providers may need to participate in targeted continuing education to become more aware of co-occurring disorders for patients with seizures.

Additionally, the lack of change in access to and use of specialty care at two time points suggests that the treatment path for children with seizures is still muddy. It is possible that parents of children with seizures are unaware of that their children should follow up with a specialty provider. In this study, most participants did not use care, but the lack of use was not because they attempted to access care and could not afford it. This suggests that parents were not attempting to access specialty care for their children. When a child has even a single seizure, parents should be informed and educated on appropriate follow up and course of action for treatment as well as prepared in the event another seizure occurs.

Though in this study, patients with more symptoms accessed care, measurement of efficacy of treatment, length of treatment, and type of treatment was not explored. There is limited research in evaluating effectiveness of mental health treatments among the epilepsy population and the research published focuses on a few psychotherapy options (CBT, ACT). Therefore, future research should further examine which treatment options are best for those struggling with this chronic condition. With more information on efficacy and treatment

trajectory and prognosis, education can be provided to pediatric providers and neurologists in order to increase referrals for continued care and promote psychoeducation for patients and their families.

Future research should focus on children specifically with an epilepsy diagnosis to capture accurate information for the target population. The distinction between those with epilepsy and those who have had one seizure is important because those who have experienced one seizure will likely not go on to have the same challenges as a child with epilepsy who experiences frequent seizures. The type of epilepsy also informs disease trajectory and intervention needs. However, as seen with this study, those with epilepsy are often a hard population to capture and data for these patients is often recirculated by use of national samples or shared data. Pediatric patients, especially those with special health care needs, are a challenging and vulnerable population to research.

Further, it will be important to also examine the type of specialty care accessed, including whether it was specific to the diagnosis of epilepsy (e.g., neurology, neuropsychology), and to what extent mental health care was provided (i.e., time, course, frequency), and the type of provider involved (e.g., social worker, psychologist, psychiatrist, Nurse Practitioner etc.), and whether insurance mediated access and use for specific treatment plans.

Future research should also create reliable and valid measures of mental health and specialty care access and use in children who experience seizures. To do this, it is suggested that original surveys be created as opposed to archival and widely available data; or that reliably be examined for measures of access and use of care in surveys that are widely available.

Most non-White participants in this sample had public insurance or were uninsured. The original hypotheses postulated that those with public insurance or uninsured would have less

access and use of care. Therefore, it raises question as to why there appears to be a pattern of public insurance or no insurance coverage among those who identify as a minority race, and if additional systematic inequities result in racial discrimination of access and use of care. No hypotheses about race were investigated in this study, but given racial disparities in insurance type, future research should be conducted to examine the impact of race on insurance type among pediatric epilepsy patients. There should also be some consideration regarding data collection processes and the hardships that are often associated with collecting participant data among groups with additional housings, financial, and social hardships. For example, it may be beneficial to attempt to gather information in non-business hours at place of residence or gather information at places of work in some communities.

This study found that, regardless of insurance type, care was underutilized among pediatric patients who have had at least one seizure in the last 12 months. This pattern was observed at two time points with no significant difference between them. This implies that a gap in care remains for this population, but that insurance is likely not the leading barrier. Those with more mental health symptoms had more access and use of care, which is a positive sign that those with possibly more needs are being treated. Future research should be aimed at exploring the strength of other barriers to care for this population and how to implement strategies to mitigate the effects of these barriers.

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## Appendix A

Variable Name	Not True	Somewhat True	Definitely True
Question 1: Is generally well behaved, usually does what adults request.	2	1	0
Question 2: Has many worries, or often seems worried	0	1	2
Question 3: Is often unhappy, depressed or tearful.	0	1	2
Question 4: Gets along better with adults than with other children.	0	1	2
Question 5: Has good attention span, sees chores or homework through to the end.	2	1	0

