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Research Article

**IMPACT OF PEDIATRIC EPILEPSY ON HEALTH-RELATED
QUALITY OF LIFE**

Mohammed Ahmed Alshadwi Alzahrani ,
Saleh Ali Alqarni,
Ebtsam Ali Alghamdi,
Riyad Mohammed Alghamdi,
Hussain Abdullah Alghamdi,
Ahmed Saeed Alshadwi,
Ahmed Abdullah Alghamdi,
Shakeer Mohammed Ali

Article Received: October 2022**Accepted:** November 2022**Published:** December 2022**Abstract:**

Pediatric epilepsy is a chronic neurological disorder affecting millions of people globally. It is a heterogeneous condition that varies in terms of seizure variables, etiology, management, and neurological pathology presence. Some common symptoms associated with the condition are convulsions, jerking, and loss of control of bladder and bowel movements. Individuals are living with the condition, particularly children, experience numerous problems ranging from behavioral, educational, psychological, social, educational, and cultural issues, which in turn negatively impact their life. Therefore, this document investigates how PE impacts life. PE impacts the lives of individuals living with the condition and their families. It is associated with learning difficulties, especially in the CWE, causing education underachievement in their education. Moreover, the condition interferes with child social life, where they are excluded from social and physical activities. In schools, CWE experiences limitations when playing with other children. Lastly, the disorder contributes to emotional and behavioral problems.

Corresponding author:**Mohammed Ahmed Alshadwi Alzahrani,**

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INTRODUCTION:

Pediatric Epilepsy

Epilepsy is a chronic disorder affecting many people globally. According to the WHO, approximately 50 million people worldwide live with this condition, making it one of the most prevalent neurological conditions globally. In other words, 1 in 100 people has epilepsy. The WHO report shows that nearly 80 percent of epileptic people live in low and medium countries (World Health Organization. n.d.). Estimably, 70 percent of the people living with the condition are more likely to live seizure-free if diagnosed and treated correctly (World Health Organization. n.d.). 1.2 percent of the American population had active epilepsy in 2015, accounting for over 3 million people who are epileptic in the country. The data showed that the adults were three 3 million and over 400,000 were children (CDC,2020, September 30). The CDC estimates reveal that about 6 in every 1000 children between 0 and 17 years are epileptic. Adults living with this condition first encountered seizures when they were young or in adolescence. It is a heterogeneous condition that varies in terms of seizure variables, etiology, management, and neurological pathology presence. It is mainly characterized by the recurrence of brief episodes of involuntary movement that may be partial (part of the body) or generalized (the entire body) and sometimes is characterized by the loss of consciousness and control of bladder and bowel function. The unpredictability of seizures recurrence for the people or children living with this condition is a constant threat to them and their families.

Aside from the unpredictability of the seizure, numerous ever-present factors affect this group of people and their families, including behavioral, educational, psychological, social, educational., and cultural (Subki, Mukhtar, Al-Harbi, Alotaibi, Mosaad, Alsallum, & Jan 2018). It is estimated that around two-thirds of children with epilepsy (CWE) outgrow seizures by the time they reach their teenage (World Health Organization. n.d.). Wagner, Sample, Ferguson, Pickelsimer, Smith, & Selassie (2009) outline that children can eliminate seizures and thwart their side effects with an organized care system. How PD impacts the lives of individuals differs significantly from one person to the other. The epilepsy implication on life is a topic that is widely under the focus of many scholars. While epilepsy lasts for a lifetime, the implication of the recurrent seizures on the child's social well-being, psychological functioning, and health status is crucial in identifying the child's and family's needs and planning for treatment (Subki et al., 2018). This paper will evaluate how pediatric epilepsy (PD)

impacts the lives of school-going children and their families. Moreover, it will focus on the measures that the parent or guardians put in place to mitigate how epilepsy impacts the lives of the children and their lives. Most studies paid more attention to evaluating the impacts of epilepsy on the child's cognitive functioning, behavior, academic achievement, and neuropsychiatric functioning. Although the severity of PD can be managed with the proper diagnosis and treatment, it negatively impacts the child's life and their families.

Analysis of the impact of Pediatric Epilepsy on Quality of Life

Epilepsy is a disorder of repeated types of seizures. Falco-Walter, Scheffer, & Fisher (2018) outline that different types of epilepsy vary according to either the causes, extent, or effects. Seizures are generally categorized into two categories. The first category is generalized epilepsy, in which seizures affect the entire brain. In this type of epilepsy, there are no actual areas brain areas that are connected as the source of seizures. The second one is partial. Here, seizure only affects one area of the brain.

Generalized epilepsies are subdivided into different types. The first one is idiopathic (Wright, 2018). Here, the brain tends to act as usual during seizures. The second type of generalized epilepsy is symptomatic. Some of the most apparent symptoms of this condition are seizures, strange sensations, and behavioral changes, among others. Seizures occur as a result of the excess electrical discharges in the group of neurons in the brain. Ideally, a different part of the brain experiences these discharges. Seizures vary in intensity, and some patients may experience briefest lapses, muscle jerks, or attention to severe and prolonged convulsions. It also varies in terms of intensity, where a person may experience once per year while others experience several per day (Wright, 2018). A patient is said to be epileptic if they experience two unprovoked seizures

Falco-Walter et al. (2018) that the PD implications on people's lives differ from one child or family to another. The condition impacts the children's lives in different dimensions, including social, physical, learning ability, emotional, and behavioral. The condition affects not only the children but also the parents. Numerous studies have been conducted to evaluate how pediatric epilepsy impacts the lives of children and their parents (Camfield, Breau, & Camfield, 2003) and (Larson, Ryther, Jennesson, Geoffrey, Bruno, Anagnos, & Thiele, 2012). In their study, Camfield et al. (2003) identified that the condition negatively impacts the child's physical/

neurological, cognitive, and behavioral ability, while Larson et al. (2012) identified that it interferes with children's sleep patterns. In their study, Larson et al. (2012) found that epileptic children experienced sleep disturbance compared to those without this condition, characterized by night waking, reduced sleep durations, daytime sleepiness, bedtime resistance, and sleep onset delay. Parents with CWE reported increased changes in sleep patterns and more intense fatigue. Therefore, the impact of pediatric epilepsy on the child and parents is further discussed in detail below.

Impacts of Pediatric Epilepsy on The Child's Social Life

Social life is one of the aspects of life that is impacted by epilepsy. Social life is fundamentally important for children and contributes significantly to their developmental process. Social bonds are at the epicenter of the quality of life that children or adults live. The ability of a child to interact with other children exposes him or her to numerous opportunities to practice and learn speech and language. It is important because communication skills improve, and a child can interact with people around him. In the long run, it helps the child to improve their self-esteem. It also acts as a buffer against the negative impact the negative stress and mental health conditions. Steiger & Jokeit (2017) illustrate that social life positively impacts morbidity, health, and mortality. Limitation of the child's social life impairs the child's cognitive development. As it was outlined in the introductory part, epilepsy causes the recurrence of seizures, and it may occur at any time.

Similarly, numerous factors can impede the effective and cognitive functions necessary for smooth interactions. Ideally, psychiatric and psychological complications are common in epilepsy, which tends to hinder the processing of social information. Most epidemiological studies have revealed that the major determinants of quality of life are family interaction, social interactions, and so on, which may be limited to epileptic patients. Steiger & Jokeit (2017) further outlines that epilepsy increases the risks of having social cognitive impairments and encountering interpersonal difficulties and communication problems. The children's participation in physical activities and social engagement with their peers is crucial for their development (111). CWE cannot entirely participate in physical activities and social engagements with other children. According to the study conducted by Cianchetti, Messina, Pupillo, Crichiutti, Baglietto, Veggiotti, & TASCA study group (2015) on the experiences of epileptic children,

most parents with epileptic children responded that the seizures and the secondary problems associated with this condition often limit an individual child from full participation in social, academic, and recreational activities. Safety concerns are among the major causes that push for restricting children with epilepsy from participating in normal school activities, which seem obvious to the children. The children living with the condition are often subject to a highly restrictive environment to assure their safety in case of the reoccurrence of seizures.

One of the major requirements for managing seizures is ensuring that the patient is in a safe environment where they are free from any hazards. This is why children with seizures' social interaction or physical activities are highly monitored or limited. Restriction of the children participating intensifies their sense of social isolation. Therefore, the isolation of epileptic children from these important social learning experiences further creates a more negative perception of the self, making them perceive that they are not normal like other children and even not valued (Lew, Lewis, Lunn, Tomlin, Basu, Roach, & Martland, 2015). Parents and society need to advocate for the extra support of children with epilepsy from the school and other relevant bodies. This extra support will facilitate their full participation in the school activities like a gym or playground, which in turn will nurture interaction with other children. Involving them in the school's physical and social activities is fundamental in fostering their emotional well-being and self-perception, as well as promoting physical and social development.

The stigma associated with epilepsy is another major issue that most patients encounter. Lack of sensitivity among the patients towards CWE affects their mental health and adaptive behavioral responses. Society tends to have a negative connotation toward children with epilepsy, as they are viewed as abnormal or unhealthy, or even possessed. For instance, in some societies, especially in developing countries, epilepsy is believed to be attributed to the evil powers caused by the child's parents or their families, and due to this reason, they are excluded by society (Ronen, Streiner, & Rosenbaum, 2003). In the surveys conducted in Taiwan and India, 7 percent and 15 percent of the people who responded believed that epilepsy was a form of insanity. On the same note, 18 and 40 percent of the respondents, respectively, that children with epilepsy should not enroll in schools or they should not play with other children. 72 and 66 percent of the respondents did not intend to marry a person with epilepsy (Ronen et al., 2003). Thirty-one

percent of the respondents in Taiwan perceived that epileptic people should not be employed in jobs like other employees (Ronen et al.,2003).

Most children with this condition are excluded from social activities with other classmates and are often teased and bullied or even discontinued from school due to behavioral issues. These factors tend to reinforce the child's negative perception of themselves and how society views them as they are alienated from usual social and learning experiences that promote self-esteem and normal social development (Kwong, Lam, Tsui, Ngan, Tsang, Lai, & Lam, (2016). Mao, Wang, Zhang, Wang, Zhao, Peng, & Ding (2022), in their study, identified that one of the factors that affect epilepsy patients is social attitudes and their condition. Many of the patients encounter stigmatization which limits their participation in social interactions or activities.

Pediatric epilepsy cause language dysfunction, especially when it develops in early childhood (Baumer, Cardon, & Porter, 2018). As a result of this, the language patterns in the brain may be distorted, leading to developmental difficulties, and a child may encounter challenges in communication skills acquisition in comparison to other children at their age. Communication dysfunction is normally associated with partial epilepsy with its roots in the left hemisphere of the brain. In most of these cases, the language dysfunctions take the form of a general reduction in a large class of verbally based skills. This often affects the child's ability to read and write in their school-going years. However, many forms of generalized epilepsy have no specific impact on a range of functions, including those that involve language. However, other forms of epilepsy have definite patterns of language disturbances. One of the common language disturbances caused by epilepsy is aphasia (Baumer et al.,2018). Children with language disturbances linked to epilepsy experience seclusion from social activities and social interactions with other children as they cannot communicate with them properly.

Impact Of PE On the Child on Learning and Academic Life

The effect of PE on a child's academic or learning life has been under study by numerous scholars. Some of the studies indicate that PE has an impact on child education. For instance, Johnson, Atkinson, Mugeridge, Cross, & Reilly (2022) included 20 school-aged children with active PE and were taking anti-seizure medications, 68 parents, and 56 school staff to evaluate the effect of PE on the CWE learning and behavioral patterns. The researchers found that 53 % of the CWE felt that their condition

affected their learning, including some aspects like concentration, memory, attention, and physical and emotional well-being (Johnson et al., 2022). Also, the children reported that PE lowered their level of confidence and increased tiredness, thus contributing to their lower education performance. They also responded that taking anti-seizure medications (ASMs) increased emotional reactivity and irritability. And they also mentioned that PE was linked with restrictions and stagnation in school. Similarly, 85 percent of the parents who participated in the study concurred that PE has implications on the children's behavior /learning, while more education staff believed that the condition affects learning more than behavior. Sixty-one percent of the school staff believed that PE affected education more, while only 45 percent believed that it affected behavior more than learning (Johnson et al.,2022).

Other studies' findings show that epilepsy has no impact on the child's academic achievements compared to those without the same condition. For instance, Wo, Ong, Low, & Lai (2017) conducted a systematic survey of the articles that focused on the impact of PE on the child's academic achievement. They identified that 70 percent of the studies reported CWE scored lower grades *visa vis* the healthy children. However, the other 30 percent of studies identified no differences in academic achievement between the CWE and healthy children (Wo et al.,2017). CWE showed stable academic scores between 2 and 4 years after joining the school; even the academic performance for the CWE seizure frequency improved (Wo et al.,2017).

Even though the overall intellectual ability of the CWE compares with the healthy children, they tend to experience learning and academic difficulties when compared to the latter. These learning difficulties contribute to the CWE's academic underachievement. Even CWE with normal intelligence, most of them report deficits in areas linked to learning and thinking abilities. In particular, they fall short in specific areas of memory, concentration and attention, and organizational and academic achievement (Wo et al., 2017). Ideally, most of the CWEs do not fit the normal school definition of learning disabilities as their writing, reading, spelling, and math skills can be developed appropriately. Nevertheless, they encounter significant difficulties in learning which is caused by their weaknesses in one of the areas mentioned above. Some CWEs have normal learning difficulties (developmental delays in learning) attributable to extensive brain abnormalities. More often, they present a variety of specific learning problems linked

to focal brain abnormality. For instance, CWE with mesial temporal sclerosis may have permanent short-term visual memory or auditory problems.

Another factor that is associated with CWE academic underachievement is transitory learning problems, which are attributable to AEDs, seizures, and fatigue. For instance, seizures, seizure aftermath fatigue, or even confusion can interfere with a child's learning process for a given period, i.e., hours or minutes. Indeed, visible seizures are known for interrupting the child's learning, but the evidence shows that epileptiform discharges occurring in the brain during the seizures also interfere with their learning. These disruptions caused by the epileptiform are known as Transient Cognitive impairment (TCI). Finally, studies have shown that children with poorly managed epilepsy tend to experience increased fatigue, which is a crucial factor associated with reduced chances of attending school or even joining learning opportunities (Çilliler, & Güven, 2020)). The school staff and parents report the CWE fluctuating performance between days showing that the transitory disruption impacted the children's academic performance. To address academic underachievement among the CWE population, more effective learning strategies can be put into account. For instance, teachers need to utilize repetitive instruction techniques to improve CWE academic achievement.

As outlined above, attestation disorder is one of the behavioral problems that the CWE experiences. It is estimated that 8% of the CWEs have problems with attention (Epilepsy Foundation. n.d.). Attention deficit/ hyperactivity disorder is associated with easy distractions, fidgety, frustration, forgetfulness, and impulsiveness. It makes social connections and the learning process problematic, regardless of an individual's cognitive abilities. Attention disorder among CWE contributes in a greater proportion to the child's academic underperformance.

Emotional and Behavioral Issues

The behavior among the CWE is another topic that has received huge attention from researchers. Berg, Altalib, & Devinsky (2017) conducted a systematic review on the same subject and identified that most previous studies support that CWE experienced a high level of psychiatric, emotional, and behavioral disorders than any other group. However, the researchers state that the previous studies' findings are subject to biases as they rely on the parent proxy completed instruments to assess the behavioral and psychiatric patterns of their children. Johnson et al. (2022) identified that most CWEs utilizing ASMs

reported increased emotional reactivity and irritability. Aldenkamp, Besag, Gobbi, Caplan, Dunn, & Sillanpää (2016) concur with Johnson et al. (2022) findings where they illustrate that some ASMs contribute to psychiatric and behavioral disorders among epilepsy patients. Therefore, it is recognized that CWE exhibit a particularly higher rate of lifetime risk for mental and behavioral health (Martinos, Pujar, Gillberg, Cortina-Borja, Neville, De Haan, & Chin, 2018).

According to the study conducted by Martinos et al. (2018), 40 percent of the children included in the study with convulsive status epilepticus (CSE) had mental and behavioral disorders compared to those with non CSE with 28 percent. The above data shows that CWE has elevated rates of having emotional and behavioral comorbidities, unlike the general healthy population. The most common behavioral and emotional/ psychiatric issues apparent to the CWE include increased levels of depression, anxiety, aggression, and hyperactivity, as well as the irrational cases of rage which occur in some instances. Studies have shown that a bigger number of CWEs tend to display behavioral problems, especially in the period before their first recognized seizure.

Indeed, epilepsy is a complex condition that may often begin exhibiting itself through behavioral changes and convulsions. A small proportion of the CWE tends to exhibit behavioral or verbal aggression, which occurs with no or minimal provocation. There is a scarcity of studies focusing on the causes of verbal or behavioral aggressiveness among this group of CWE, and factors contributing to these aggressions are well understood. One of the causal mechanisms associated with behavioral dysfunction among CWE is epileptiform discharge in the brain, which causes confusion in functions, then affects the behavior (Berg, Altalib, & Devinsky, 2017). Other studies suggest that these behavioral aggressions among CWE are attributable to the production of epileptic activities from certain abnormal regions of the brain, and this may be worsened by the use of some anti-epileptic medications (Wright, 2018).

Berg et al. (2017) describe the numerous factors that are linked to mental health and behavioral difficulties in the epileptic population. Just like other disorders, the psychological implications in epileptic persons vary significantly. While some with this condition encounter minimal mental health problems, it is severe in others, accompanied by behavioral difficulties. Therefore, this demands the address of the condition at an early stage with the most effective

intervention methods, including behavioral and drug therapy, to minimize its interference with the patient leading them to live a more comfortable life. Despite that the behavioral and mental health problems associated with PE are also identifiable in people without PE, they are common in those living with the disorder. Epileptic people are 5 times more likely to exhibit behavioral and mental health issues, with a rate ranging from 30 to 50 percent, than the general population, with an incidence of 8.5 percent (Epilepsy Foundation. n.d.). The factors that are connected with causing mental health problems among CWE are categorized into two broad categories, including internal and external factors. The internal factors are a result of the functions of the structure of the brain, while the external factors are not biologically based but cause mental or behavioral problems. A good example of external factors is the reaction of other people to epilepsy. This may result in feelings of depression and anxiety. Often, both external and internal factors contribute significantly to mental health issues.

Wright (2018) outlines that the brain controls an individual's behavior, perception as well as motor control, so it is not surprising that the disruptions of normal brain functions, such as those caused by epilepsy, could impact the behaviors. However, it is not yet identified how and why these disruptions of the brain functions alter the individuals with epilepsy behaviors. The seizure types that individual experiences contribute significantly to the form and extent of the behavioral changes. For instance, a child with generalized seizures has higher odds of having hyperactivity and inattention problems in comparison with partial seizures.

Similarly, the more intricate partial seizure tends to present more profound repercussions. For instance, limbic system-related seizures pose a risk of personality and behavioral disorders. A limbic system is a group of structures in the brain which generates and controls emotional responses. On the other hand, behavioral issues can also result from factors caused by the external environment without a direct link to the underlying mechanism of epilepsy. For example, external factors may include environmental conditions like how society perceives persons with PD. Convulsions and epilepsy can result in stigma, particularly from people who are not aware of the disorder. The negative reactions and misconceptions about the conditions and seizures from people can result in serious psychological problems like depression and anxiety. Mao et al. (2022) illustrate CWE's own reactions to their condition as the root

cause of health-cause of mental health and behavioral problems like fear which later intensifies to more chronic anxiety or low self-esteem that are associated with academic underachievement. Low awareness about seizures and epilepsy from society accelerates stigmatization, especially towards CWE (Mao et al., 2022). For CWE, self-perception and self-esteem can be critical to success and happiness throughout life. Understandably, the self-esteem of CWE depends on numerous factors, but the main ones are family support and access to proper treatment.

As mentioned above, the side effects of anti-seizure medications are another external factor that influences behavioral and mental health issues among CWE. The ASMs are intended to inhibit excessive electrical activity in the brain. It helps in curbing abnormal surges of seizures. The shortcoming of this treatment is that it may cause cognitive and behavioral dysfunctions.

In their study, Nabbout, Camfield, Andrade, Arzimanoglou, Chiron, Cramer, & Camfield (2017) received numerous responses from parents who outlined a variety of instances where they identified the changes in children's mood accompanied by heightened aggression. The most cited instance is the use of high doses ASMs which coincided with behavioral alterations, including verbal and physical aggressions and irritability. Physical aggression occurs in different forms. For instance, a child with the condition may decide to hit another with the stone. When the behavioral side effects of CWE become uncontrollable, individuals may choose to reduce the dosage of the drug or eliminate it completely while adding other drugs that may be effective in managing seizures while reducing side effects. Secondly, the increased verbal and physical aggressions and irritability signify the seizure onset. In most cases, the behavioral changes tend to occur hours or days before seizure recurrence. During this period, the external stimuli can further irate the CWE, thus increasing their aggression or frustration. Therefore, it is important for the teachers to create a conducive environment for the child that reduces frustration, like giving a manageable academic workload.

Thirdly, some children experience sudden verbal outbursts and physical aggression. CWE in this category presents a serious challenge to their families, educators, and healthcare practitioners. The child's aggression episodes may occur with no or minimal provocations. This may go on for a while. Parents with CWE often report the trajectory for episodic physical or verbal aggression. Some CWE

experience explosive behavior, which is precipitated by an environment they perceive to be noxious. Their physical aggressions and verbal outbursts are caused by their challenge to control the impulses like anger. Therefore, due to this nature, CWE experiences numerous limitations both in their neighborhood and school. They spend most of their time alone as no children will be willing to play or interact with them. In their schools, CWEs are more likely to be suspended due to their verbal and physical aggression. The emotional and behavioral effects of PE can be controlled by subjecting a child to an environment with less provocative external stimuli (McLaughlin, Schraegle, Nussbaum, & Titus, 2018). For instance, the teachers should make sure the child is not bullied or belittled in school.

Some parents report reduced sleep patterns with their CWE, especially before, during, and immediately after the seizure at night (Larson et al., 2012). Most of CWEs encounter loss of sleep at night when they have seizure recurrence, and they tend to sleep during the daytime, especially while in school, which contributes to poor academic underperformance.

The Impact on The Parents or Families

Most of the studies center on assessing the impact of PE on the individual living with conditions but disregarding its impact on the parents or families of the CWE. The families of the CWE pass through a hard time due to epilepsy which disrupts their life significantly. Families of THE CWE experiences anxiety and feeling of helplessness during and after the child's seizure cycles and after the epilepsy is diagnosed (Ostendorf, & Gedela, 2017, November). The parent is afraid of the unknown and often experiences overwhelming feelings of depression and sadness as they grieve for the condition of their child and how it may negatively impact his or her life. They grieve about the changes that would be made because of epilepsy and the dreams that their child will not achieve (McLaughlin, Schraegle, Nussbaum, & Titus, 2018). The feelings of grieving are normal to the parents, and it will take time for them to come to terms with their child's condition and acknowledge that it is a lifelong problem.

CONCLUSION:

Numerous studies have been conducted to evaluate how PD implicates the lives of children and their parents (Camfield et al., 2003) and Larson et al., 2012). The condition negatively impacts the child's physical/ neurological, cognitive, and behavioral ability (Camfield et al., 2003), while Larson et al. (2012) identified that it interferes with children's sleep patterns. Emotional and behavioral problems

among CWE can be managed through a combination of strategies, including behavioral therapeutic interventions, psychiatric follow-up, and instruction methods, among others. The condition is associated with depression, anxiety, and low self-esteem, among other psychological problems, especially for adolescents. This necessitates the parents, school, and the entire society to focus on providing a supportive environment for the CWE. In the schools, the teaching staff should try to incorporate the children with conditions in social and physical activities. However, they need to be a bit cautious about the environment they subject these children to avoid injuries just in case of convulsions. Society should not view CWE as children who are normal and needs to mind their language while describing them since it may negatively affect them emotionally and behaviorally. Most CWE begins exhibiting verbal and physical aggression and become irritated, while other become depressed and anxious when negatively described their health status. Although it is understandable that parents care more about the safety of their children, they need to allow them to interact with their peers in the neighborhood, as this will not only improve their communication skills but will also improve their mental well-being. Lastly, the parents' needs need to seek therapy for the CWE as well as themselves.

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