This letter is been written to bring attention to a matter that is close to our hearts: the impact of epilepsy on children and their families. With this letter, our goal is to raise awareness within our community and to encourage a collective effort to acknowledge and confront the difficulties encountered by children living with this condition, as well as the significant strain it imposes on their families.

Epilepsy is a chronic neurological disorder characterized by recurrent seizures that significantly impact the quality of life of affected children and their families, affecting millions of individuals worldwide \(^1,2\). The reported incidence rate of epilepsy in children ranges from 41 to 187 per 1,000 children, whereas the prevalence rate in developed and underdeveloped nations is 3.2–5.5 and 3.6–44 per 1,000 children, respectively \(^3\).

Seizures, the hallmark of epilepsy, can occur unexpectedly, disrupting daily activities and creating a perpetual state of uncertainty for both the child and their parents. However, if a first-line anti-epileptic medication is taken as soon as possible, nearly 70% of patients can become seizure-free.

Despite the wide availability of effective anti-epileptic drugs, a substantial portion of the population, approximately 90%, still resides within the confines of the “treatment gap” \(^3\).

For these children, the impact of epilepsy extends well beyond the seizures themselves. The emotional burden it imposes is significant. Consider the constant fear they live with—fear of when the next seizure might occur, concern over potential physical injury, and embarrassment due to the stigma surrounding this often misunderstood condition. This emotional stress can result in increased anxiety, depression, and low self-esteem.

Education, too, substantially suffers as children with epilepsy navigate a path fraught with obstacles \(^4\). Frequent absences, doctor visits, and medication side effects can hinder their academic achievement and social integration. As a result, isolation often becomes an unintended companion for these children, stemming from a society that frequently lacks understanding of their condition and opts to perpetuate ignorance rather than foster empathy.

Despite evidence of both economic growth and the concurrent advancement of medical procedures and services, Asia remains a continent with limited resources. Many cultures harbor the unfavorable belief that individuals with epilepsy are incapable of contributing in the same ways as their healthy counterparts. Regrettably, a growing treatment gap is becoming increasingly evident each day, as people often opt for multiple healing modalities simultaneously \(^3\). However, the burden does not fall solely on the children affected by this condition. Parents bear the immense responsibility of their child’s epilepsy, acutely feeling the impact of each seizure and its potential re-
percussions. The constant worry, sleepless nights, and anxiety about their child’s future exact an immeasurable toll on their mental health. Financial strain exacerbates the situation, with medical bills and the need for specialized care adding an additional layer of stress.

The effects of a child’s illness are far-reaching, impacting not only the parents but also the siblings. These brothers and sisters directly observe the suffering of their sibling, and they may feel neglected or overshadowed by the constant challenges faced by the family. They also deserve attention and support during these difficult times.

Numerous studies have been conducted across various nations and cultures on family quality of life, particularly focusing on the impact of epilepsy. These studies frequently report negative effects. Families with children who have epilepsy often experience heightened stress, communication challenges, insufficient social support from relatives, and poorer financial outcomes. In an Austrian study that used the Family Assessment Measure III (FAM-III) to assess families, including those with children who have epilepsy and cognitive impairments, 26% exhibited signs of family dysfunction. This is in stark contrast to the 6.5% observed in the control group. Furthermore, an Indian study found negative outcomes in 42% of families. Factors associated with poorer outcomes included a shorter duration since diagnosis, more frequent seizures, the use of multiple anti-epileptic drugs (polypharmacy), and an increase in behavioral problems in the child with epilepsy [5].

It is crucial for society to unite as a compassionate community, providing support and understanding to individuals affected by epilepsy. We must prioritize funding and research to seek advancements in treatment options, with the ultimate goal of finding a cure. To combat the widespread misconceptions about epilepsy, we need to implement awareness campaigns and educational initiatives that promote inclusivity and dispel the stigma that unjustly affects many innocent lives.

In conclusion, we implore for the start of a dialogue and the instigation of change. Let us come together as a society that rejects ignorance and collectively strives to support these innocent lives. It is only through empathy, the allocation of resources, and education that we can hope to alleviate the burden borne by children with epilepsy and their families.

“Epilepsy is an illness that affects obviously the child and clearly the parents, but an often-forgotten player in it is the child’s siblings.” - Nicole Danforth, MD.

Conflicts of interest

No potential conflict of interest relevant to this article was reported.

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