

Perceived Stigma in Children with Epilepsy

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Abstract

Children with epilepsy are more likely to have poorer quality of life (QOL) than the general population. Stigma is a global phenomenon associated with several chronic diseases with great negative impact on patients and their families and deleterious consequences in their QOL. People with epilepsy report that stigma is one of the greatest challenges that they face. Adolescents can be mentally and emotionally fragile, therefore, epilepsy can stigmatize children and impair their independence, social abilities, peer relations, self-esteem, mood, and cognition during this turbulent stage of life. To develop and implement interventions to improve the psychosocial health of individuals with epilepsy, it is important for researchers and clinicians to understand the effects of the stigma accompanying epilepsy. Our previous study using Child Stigma Scale showed that children with frequent seizures perceived themselves as significantly more stigmatized compared to seizure-free children ($p < 0.01$). These findings suggest that a relationship may be seen between current seizure frequency and perceived stigma. On the other hand, the responses of children with epilepsy on the Child Stigma Scale were different depending on the localization of EEG paroxysmal abnormality (PA). The scores of all questions were significantly higher in the frontal group than those with PA in other regions ($p < 0.01$). Frontal EEG PA may function as a mediator of emotional responses such as stigma. Organizing children and adolescents support groups and effective educational intervention programs for children with and without epilepsy should be given priority in reduced stigma of children with epilepsy.

Keywords: Epilepsy; Stigma; Seizure frequency; Children

Abbreviations

EEG: Electroencephalogram; QOL: Quality of Life

Sigma in Children with Epilepsy

Children with epilepsy are more likely to have poorer quality of life (QOL) than the general population because of not only the seizures, but also medical, psychiatric, and psychosocial comorbidity [1]. Epilepsy is felt to be a stigmatizing condition. Stigma is a global phenomenon associated with several chronic diseases with great negative impact on patients and their families and deleterious consequences in their QOL. Although not all people with epilepsy experience stigma, people with epilepsy report that stigma is one of the greatest challenges that they face [2]. Scambler proposed an alternative sociological construct of “epileptic identity” resting firmly on the view of epilepsy as not just a clinical problem, but also a social label [3]. Feelings of stigma have been associated with learned helplessness, depression and anxiety, impaired physical health status, reduced self-esteem, and reduced life satisfaction [4]. Some of its effects include delay in diagnosis and treatment, risk behaviors, and poor adherence to treatment [5].

In most children with epilepsy, seizure outcome is benign. However, people with epilepsy, even children, are generally considered to be at greater risk of psychopathology, such as depression and anxiety, and more likely to be socially dysfunctional than people without epilepsy. On the other hand, adolescence is the transitional stage of human physical and mental development that occurs between childhood and

adulthood. Adolescents can be mentally and emotionally fragile, therefore, epilepsy can stigmatize children and impair their independence, social abilities, peer relations, self-esteem, mood, and cognition during this turbulent stage of life [6]. Epileptic seizures are not permanently evident within individuals, but their unexpected and dramatic nature triggers a very negative impression from strangers in public places towards people with epilepsy [7]. Accordingly, there can be negative effects on social identity in children with epilepsy because of the stigma associated with having epilepsy.

A previous study using a large European survey of 15 countries found that the primary goals of epilepsy management should be ensuring that people of epilepsy remains as free from seizures as possible while minimizing the adverse effects of treatment [8]. In contrast, reducing negative attitudes such as stigma in children with epilepsy is also one of the most important goals of clinical management [8,9]. Accordingly, to develop and implement interventions to improve the psychosocial health of individuals with epilepsy, it is important for researchers and clinicians to understand the effects of the stigma accompanying epilepsy. In this general context, epilepsy health services need to be studied as key components to illness outcomes, as they can be conducive or not to favorable illness experience. However, it is not fully investigated what and how clinical manifestations can affect perceived stigma in children with epilepsy.

Seizure Frequency and Perceived Stigma

It has been not fully investigated how seizure frequency can affect perceived stigma in Japanese children with epilepsy. Stigma depends on national traits, cultures and customs. Thus, we have investigated the relationship between seizure frequency and perceived stigma in

Japanese children with epilepsy [10]. Our previous results concerned the relationship between seizure frequency and perceived stigma are described briefly as follows.

Items for the Child Stigma Scale constructed by Austin et al. [11] were developed from the literature and open-ended interviews with children with epilepsy about their concerns and fears related to having seizures. Children were asked to rate how often they felt or acted in the ways described in the items on a 5-point scale from 1 (never), 2 (not often), 3 (sometimes), 4 (often) to 5 (very often). To score, items were summed and divided by the number of items, as shown by Austin et al. [11]. A higher score reflects a greater perception of stigma.

That study showed that greater perceptions of stigma were associated with greater seizure frequency according to the child stigma scale (Table 1). Children with frequent seizures perceived themselves as significantly more stigmatized compared to seizure-free children ($p < 0.01$). These findings suggest that a relationship may be seen between current seizure frequency and perceived stigma. The findings in that study leads to the conclusion that better control of seizures may contribute to reduce perceived stigma and improve QOL in children with epilepsy [10].

Seizure frequency	Child Stigma Scale scores
Seizure free	1.58
< 1x / month	2.65
1x / month <	4.08*

*; $p < 0.0001$ for 1x/month < vs. seizure free and < 1x/month.

Table 1: Relationships between seizure frequency and Child Stigma Scale.

Region of EEG PA	Child Stigma Scale scores
Generalized	2.3
Frontal	4*
Centrotemporal	2.4
Temporal	3.2
Occipital	2.2

*; $p < 0.01$ for frontal vs. generalized, centrotemporal, temporal and occipital. EEG: Electroencephalogram; PA: paroxysmal abnormality.

Table 2: Average total score of Child Stigma Scale for each EEG PA region group.

EEG Paroxysmal Abnormality and Perceived Stigma

Several studies have examined the relationship between emotions or emotion-related constructs and abnormalities in electroencephalographic (EEG) activity. Abnormalities such as asymmetry in frontal EEG activity are ubiquitous and involved in both trait predispositions to respond to emotional stimuli and changes in emotional state [12]. On the other hand, behavioral problems in autism spectrum disorder (ASD) or attention deficit/hyperactivity disorder (ADHD) may depend on the frequency of frontal EEG paroxysmal abnormality (PA) in at least some patients [13,14].

Accordingly, frontal EEG PA may be associated with behavioral and emotional functions.

Our previous results concerned the relationship between EEG PA and perceived stigma are described briefly as follows. We have investigated the relationship between abnormal EEG findings such as localized EEG PA and perceived stigma in children with epilepsy (Table 2) [15]. We used the questionnaire as Child Stigma Scale constructed by Austin et al described as above [11]. The responses of healthy subjects on the Child Stigma Scale were between “never” and “not often” (mean, 1.1). In contrast, the responses of children with epilepsy were between “not often” and “sometimes” (mean, 2.9). Children with epilepsy showed significantly higher scores than healthy subjects ($p < 0.01$). In addition, the responses of children with epilepsy on the Child Stigma Scale were different depending on the localization of EEG PA. The scores of all questions were significantly higher in the frontal group than those with PA in other regions ($p < 0.01$) [15]. This study showed that children presenting with frontal EEG PA perceived a greater stigma than children presenting with nonfrontal EEG PA ($p < 0.01$). These findings lead to the conclusion that frontal EEG PA may function as a mediator of emotional responses such as stigma [15].

Vulnerability of Prefrontal Functions

In the developing brain, the effects of clinical manifestations such as frequent seizures and EEG PA on neuronal survival and brain growth have remained controversial [16,17]. However, several studies provide strong evidence for the vulnerability of the immature brain to seizure- or EEG PA-induced damage, which bears features of both necrotic and apoptotic death and contributes to synaptic reorganization [18-20]. In addition, prefrontal lobe is among the last cortical regions to reach full structural development, therefore, prefrontal function and its disorders are not immediately apparent [21,22]. These findings suggest that prefrontal functions show an unusually long period of increased vulnerability, in which neurons and glial cells are readily affected by many factors including frequent seizures and paroxysmal EEG abnormalities [19,21,23,24]. Accordingly, seizure severities such as repeated seizures and paroxysmal EEG abnormalities such as frontal EEG PA may induce prefrontal lobe growth disturbance or dysfunction, which leads to impairment of psychosocial functioning such as stigma.

Approach for Reduced Stigma

It is widely expected that reducing stigma should help adolescents with epilepsy experience an improved QOL. Health-related QOL is emerging as a critical measure of clinical outcome, because it takes into account the patient's own subjective view of the impact of a medical condition on personal well-being [25]. The development of self-identity and peer relationships is of critical importance in adolescence, therefore, stigma encountered at this particular life stage may greatly influence psychosocial health and self-esteem [26]. The results of these studies showed that relationships between current seizure frequency/ frontal EEG PA and impairment of psychosocial functioning such as stigma, which might reflect reduced QOL, were significant. Although stigma is multivariable, better control of seizures may contribute to reduce perceived stigma and improve QOL in children with epilepsy. Moreover, potential causes of neuropsychological impairments in individuals with EEG PA can be summarized as related to the underlying disorder, hereditary factors, location of PA, treatment effects, or psychosocial factors [27]. Gordon et al. reported a cognitive-enhancing effect of antiepileptic drugs (AEDs) such as valproate

sodium (VPA), likely to be related to reductions in PA [28]. Another study also showed that VPA administration notably decreased clinical symptoms of ADHD with frontal spikes [29]. In addition, our previous study showed that the significant efficacy of VPA treatment correlated with EEG and behavioral improvements in children presenting with frontal EEG PA [14]. These findings suggest that treatment of EEG PA might be justified even when there are no obvious seizures, if neuropsychiatric impairment is present and a possible causative role of subclinical EEG PA is suspected [15].

In addition, lack of knowledge about epilepsy has been found to be an important determinant of negative attitudes towards people with epilepsy [30]. The study by Shehata GA et al. showed that all of secondary schools students were aware of epilepsy either hear or read about it, however, most of them had wrong knowledge about epilepsy, around 90% of non-epileptic students and about 85% of epileptic students [31]. Even though all students were familiar with epilepsy, their attitudes were more negative towards people with epilepsy. Knowledge about epilepsy may be very essential in affection of attitude towards people with epilepsy. Uncorrected knowledge and negative attitudes towards people with epilepsy may be generally positively affected on people with epilepsy. The need for public education for general population children, adolescents, and adults to increase knowledge and awareness to decrease the stigma associated with epilepsy is present. Programs to address stigma must do more than just address lack of familiarity and knowledge about epilepsy to improve the social environment of children and adolescents with epilepsy [32].

The implications for QOL are not the same at different stages of life. Thus, the findings observed above should be evaluated in accordance with each stage of life. However, these investigations were insufficient to make clear these differences. Further research will be needed to discuss it.

Moreover, a number of studies provide oblique evidence that frontal EEG asymmetry may indeed mediate emotional response. Lateralized brain activity seem to be a potentially important element in the collection of properties that comprise at least some emotions. However, our study cannot conclude that frontal EEG asymmetry may affect the perception of stigma. Further studies are needed to clarify and confirm these findings.

Conclusions

Epilepsy is not just a clinical disorder, but also a social label. Achieving better control of seizures and reduction in frontal EEG PA may contribute to reduce perceived stigma and improve QOL in children with epilepsy. Moreover, misconceptions about and negative attitudes towards epilepsy may be unexpectedly high among children and adolescents, therefore, organizing children and adolescents support groups and effective educational intervention programs for children with and without epilepsy should be given priority in reduced stigma of children with epilepsy.

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