Published in final edited form as:

Epilepsy Behav. 2014 October ; 0: 38–41. doi:10.1016/j.yebeh.2014.08.004.

Examining Perceived Stigma of Children with Newly-Diagnosed Epilepsy and Their Caregivers Over a Two Year Period

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Abstract

The purpose of this study was to examine: 1) the course of perceived epilepsy-related stigma among children newly-diagnosed with epilepsy (n=39) and their caregivers (n=97) over a two year period, 2) the influence of seizure absence/presence on children and caregivers' perception of epilepsy-related stigma, and 3) congruence of child and caregiver perception of child epilepsy-related stigma. Participants completed a measure of perceived epilepsy-related stigma at three time points, and seizure status was collected at the final time point. Results indicated both caregivers ($t_{1,76} = -2.57, p < .01$) and children with epilepsy ($t_{1,29} = -3.37, p < .01$) reported decreasing epilepsy-related stigma from diagnosis to two years post-diagnosis. No significant differences were found in caregiver and child report of perceived stigma for children experiencing seizures as compared to children who have been seizure-free for the past year. Results revealed poor caregiver-child agreement of perceived epilepsy-related stigma at all three time points. These data suggest that while children with epilepsy initially perceive epilepsy-related stigma at diagnosis, their perception of stigma decreases over time. Having a better understanding of the course of epilepsy-related stigma provides clinicians with information regarding critical times to support families with stigma reduction interventions.

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Keywords

pediatric; longitudinal; seizures; agreement

1.0 Introduction

Health-related stigma refers to a social process, which can be experienced or anticipated, consisting of “exclusion, rejection, blame, or devaluation” [1]. To date, few studies have examined the perception of stigma (i.e., the internalized sense of shame that occurs from possessing a stigmatized attribute, and the anticipation that others will discriminate against the stigmatized individual) among children with epilepsy [2].

Children with epilepsy are at high risk for experiencing stigma [2]. Past research has demonstrated the long-term impact of stigma including increased depression, poor self-concept, low overall quality of life, and low disease management self-efficacy [1, 3, 4, 5, 6]; however, it is unknown if these results generalize to pediatric epilepsy. Studies have found mixed results in regard to children’s experiences of having epilepsy. One study found that the most common concern among children with epilepsy was how others perceived them [7]. A similar study conducted with children with epilepsy and their parents revealed that children believed they had experienced epilepsy-related stigma [8]. Surprisingly, Westbrook et al. (1992) found that adolescents with epilepsy believed that having epilepsy did not influence their social lives [9]. Further research is needed to examine perceived stigma in children with epilepsy and their caregivers.

Understanding both children with epilepsy and their caregivers’ reports of perceived stigma is critical because initiation of mental health treatment is often contingent upon whether caregivers believe that their children are experiencing distress. Although studies have employed children and caregivers’ reports of perceived stigma [7, 8], only one pediatric study has examined caregiver-child congruence [10]. Results from this study suggest that caregivers may be unaware of their children’s perception of health-related stigma.

As mentioned, few studies have examined the perception of stigma among children with epilepsy, and to date no studies have examined the course of perceived stigma after diagnosis. One limitation of existing literature is that it is cross-sectional. To this end, it includes participants with varying times since diagnosis, and thus, conclusions cannot be drawn about the course of children’s perception of epilepsy-related stigma. Another limitation is the absence of studies addressing caregiver-child agreement of perceived stigma among children with epilepsy. Finally, it is unclear whether the presence or absence of active seizures influences the perception of epilepsy-related stigma [9, 11, 12].

The aims of the current study were to 1) examine the course of perceived epilepsy-related stigma among children with epilepsy and their caregivers, 2) examine the influence of seizure absence/presence on children and caregivers’ perception of epilepsy-related stigma, and 3) conduct exploratory analyses to examine the congruence of child and caregiver perception of child epilepsy-related stigma. Based on prior studies, it was hypothesized that children and their caregivers would report decreasing amounts of epilepsy-related perceived

stigma from baseline (within one month after diagnosis) to two years later. It was also hypothesized that children with active seizures and their caregivers would experience higher epilepsy-related perceived stigma between one year and two years post-diagnosis than children without active seizures. Finally, little is known about parent-child agreement of perceived stigma; therefore, no formal hypotheses were made regarding the level of congruence between caregivers and children's reports of epilepsy-related perceived stigma.

2. 0 Methods

2.1 Participants

Participants were recruited from a large Midwestern, pediatric medical center as part of a larger longitudinal study examining adherence to antiepileptic medications. Inclusion criteria included: 1) children with newly-diagnosed epilepsy (i.e., recruited on the day of diagnosis), 2) children between the ages of 2–12 years, and 3) participants' ability to speak/write English for the completion of questionnaires. Exclusion criteria included: 1) children with a major developmental disorder (e.g., Autism) as per caregivers' reports and 2) children with a comorbid medical diagnosis requiring daily medications.

2.2 Measures

2.2.1 Parent Stigma Scale—The Parent Stigma Scale [13] is a five-item instrument designed to measure caregivers' belief that their child is experiencing stigma or will experience stigma from having epilepsy. Caregivers are instructed to respond to five items on a five-point scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Item scores are summed and then averaged for a total stigma score (range 1–5), with higher scores representing greater perceived epilepsy-related stigma. Coefficient alpha for the current study was 0.71 at baseline.

2.2.2 Child Stigma Scale—The Child Stigma Scale [13] is an eight-item instrument designed to measure children's belief that they are experiencing or will experience stigma from having epilepsy. Children are instructed to respond to the eight items on a five-point scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Item scores are summed and then averaged for a total stigma score (range 1–5), with higher scores representing greater perceived epilepsy-related stigma. Coefficient alpha for the current study was 0.81 at baseline.

2.2.3 Seizure Status—Presence or absence of seizures was collected through medical chart review and caregivers' responses to the following questions 1) "How many seizures has your child had since their last clinic visit?" and 2) "Since your last clinic visit, have you noticed seizure activity or staring spells?" Children experiencing one or more seizures and/or staring spells between one and two years post-diagnosis were categorized as having seizures while those who did not, were coded as not having seizures. Given the variability in both type (i.e., absence, tonic-clonic, etc.) and frequency (i.e., 0 to 100+) of seizure status, we were unable to use a more specific definition of seizure status.

2.2.4. Background Information Form—The Background Information Form was completed by caregivers and contained information regarding family composition; child's age, race, and sex; and caregivers' age, race, sex, marital status, education, and occupation. Revised Duncan Score, an occupation based measure of socioeconomic status (SES) was calculated using information obtained from the Background Information Form. Scores on the Revised Duncan Score range from 15–97, with higher scores equating to higher SES [14].

2.4. Procedure

Research staff approached caregivers of children with epilepsy during their scheduled epilepsy clinic visit. After obtaining consent/assent, caregivers completed a demographics questionnaire. Children and their caregivers returned to the clinic approximately one month post-diagnosis and every three months thereafter for follow-up appointments. Research study visits coincided with follow-up clinic appointments, at which time caregivers completed a series of questionnaires, including the Parent Stigma Scale. Similarly, children 8 years and older completed measures, including the Child Stigma Scale. For purposes of the current study, stigma data from one month, one year, and two years post-diagnosis were used. Caregivers were compensated for their time and participation with a \$10 gift card for completing the questionnaires. The protocol and consent forms were approved by the Institutional Review Board.

2.5 Statistical Analyses

Hierarchical Linear Modeling (HLM) analyses were conducted to test whether children with newly-diagnosed epilepsy and their caregivers reported decreasing epilepsy-related perceived stigma (i.e., scores on the Parent Stigma Scale and Child Stigma Scale) over time. The outcome variable of interest was epilepsy-related perceived stigma, and time was the independent variable. Separate analyses were conducted for caregiver and child data using three time points (baseline, one year post-diagnosis, and two years post-diagnosis). Independent sample t-tests (caregiver and child) were employed to examine differences in child and caregiver perceived stigma between one year and two years post-diagnosis. Finally, intra-class correlation coefficients were calculated for the caregiver-child dyads ($n=37$) to examine the agreement between child and caregiver perception of epilepsy-related stigma.

3. 0 Results

Of the 110 eligible participants, 105 families agreed to participate in the larger study. However, 8 participants were excluded in the current study for the following reasons: 2 did not return to clinic after diagnosis, 1 terminated participation in the study due to being seen in another clinic, and 5 participants had missing questionnaire data at baseline. The current cohort included 97 caregivers of children with newly-diagnosed epilepsy (See Table 1).

Of the 46 eligible child participants, only 39 child participants were included in the current study. Seven participants were excluded for the following reasons: 2 did not return to clinic after diagnosis, 2 had caregivers who did not want their children to complete questionnaires,

2 did not complete questionnaires due to having a learning disability and being unable to comprehend the questionnaires, and 1 terminated participation from the study due to being seen in another clinic. The resulting child cohort included 39 children with newly-diagnosed epilepsy (See Table 1).

3.1. Perceived Epilepsy-Related Stigma

HLM results revealed both caregivers ($t_{1,76}=-2.57$ $p<.01$) and children ($t_{1,29}=-3.37$, $p<.01$) reported decreasing epilepsy-related stigma over time. Figure 1 displays caregiver and child reports of epilepsy-related perceived-stigma over time. Caregivers' stigma scores were as follows: baseline ($M=2.15$, $SD=0.76$), one year post-diagnosis ($M=2.0$, $SD=0.73$), and two years post-diagnosis ($M=1.88$, $SD=0.70$). Child stigma scores were as follows: baseline ($M=2.11$, $SD=0.87$), one year post-diagnosis ($M=1.63$, $SD=0.69$), and two years post-diagnosis ($M=1.61$, $SD=0.55$).

3.2 Seizure Status

No significant differences were found between children who experienced seizures versus those who did not as per caregivers' reports ($t(65) = .93$, $p = 0.52$) or children's reports ($t(25) = -.89$, $p = 0.75$) of perceived stigma. Specifically, caregiver stigma scores for children actively experiencing seizures ($N=12$, $M=2.05$, $SD=0.74$) were not statistically different than children not experiencing seizures ($N = 55$, $M=1.84$, $SD=0.69$). Additionally, child stigma scores for children actively experiencing seizures ($N=3$, $M=1.38$, $SD=0.65$) were not statistically different from children not experiencing seizures ($N=24$, $M=1.68$, $SD=0.56$).

3.3 Caregiver and Child Congruence

Intra-class correlation analyses indicated poor caregiver-child agreement at baseline ($r=.01$, $p = .49$), one year following diagnosis ($r=-.06$, $p = .56$), and two years following diagnosis ($r=-.49$, $p = .83$). Specifically, caregivers ($M= 2.35$, $SD=0.73$) reported higher levels of perceived stigma compared to children ($M=2.11$, $SD=0.89$) at baseline, as well as two years after diagnosis (caregivers: $M= 1.75$, $SD=0.61$; children: $M=1.59$, $SD=0.56$). In contrast, children ($M=1.95$, $SD=0.80$) reported higher levels of perceived stigma compared to caregivers ($M= 1.61$, $SD=0.72$) at one year after diagnosis.

4. 0 Discussion

To our knowledge, this is the first study to use a longitudinal design to assess perceived-stigma among children with newly-diagnosed epilepsy and their caregivers. Study results indicated that although children with epilepsy experience stigma, their level of epilepsy-related stigma significantly decreases over time. One explanation for their reduction in perceived stigma is that as children adapt and adjust to their epilepsy diagnosis, their perception of stigma decreases. As families work with their children's healthcare providers to effectively manage their children's epilepsy, families regain a sense of control resulting in the illness becoming less stigmatizing. It is also possible that because caregivers' of children newly diagnosed with epilepsy have a tendency to shift recreational activities from outside the home to inside the home, they reduce the chance for their children to experience discrimination and subsequent perceived stigma [15].

Having a better understanding of the course of pediatric epilepsy-related stigma has important treatment implications. By understanding that perceived epilepsy-related stigma is greatest around the time of diagnosis, clinicians can target stigma-reduction interventions during this time period. Currently all stigma-reduction interventions with epilepsy are done at the community-level and focus on overt discrimination [16] with no published interventions at the individual level. Effective stigma-reduction interventions with other populations include psychoeducation, psychoeducation plus cognitive restructuring, and acceptance and commitment therapies [17] and may be beneficial in pediatric epilepsy. Although one might argue that stigma interventions are unnecessary given the natural decrease in stigma over time, the long-term negative impacts of stigma found in adult studies [3, 6] make it pertinent for clinicians to potentially intervene prior to stigma decreasing on its own. While it is unknown if children experience similar long-term negative impacts of stigma, it is important to be cognizant of this possibility, as well as explore this area in future studies.

This study also demonstrated no differences in epilepsy-related stigma for children with active seizures compared to children who have been seizure-free between one and two years post-diagnosis. One potential reason for this finding may be the variability of seizure occurrence in children. For example, children would all be classified as having seizures whether they experienced one seizure or multiple seizures. Combining heterogeneous seizure types (i.e., absence, tonic-clonic) into one category and a small sample size may have made it difficult to detect group differences.

Finally, study results demonstrated poor caregiver-child agreement during all assessment points, with caregivers reporting more stigma initially and 2-years following diagnosis and children reporting higher perceived stigma one year following diagnosis. One explanation for caregivers' report of higher amounts of stigma may be their own fear of their child being excluded or judged by others (*e.g.*, other caregivers refusing to let their own children play with children with epilepsy due to fear of not knowing what to do in case of a seizure). Interestingly, children reported higher levels of stigma than their caregivers at one year post-diagnosis; however, it is unclear why this is the case and requires further investigation. Additionally, low agreement between caregiver and child reports may be due to the difficult nature of rating another person's internal experience. This is consistent with the larger literature, which demonstrates that caregivers and children do not agree on internalized or intrinsic factors [18, 19]. While this finding is consistent with other studies, it highlights the need for healthcare and mental health clinicians to be sensitive to possible stigma experienced by children with epilepsy. Even if caregivers do not report concerns, clinicians should routinely inquire about stigma with children themselves. This finding also highlights the importance of psychoeducation for caregivers about perceived stigma experienced by children with epilepsy, long-term implications of experiencing stigma, and what caregivers can do should their child experience stigma now (or in the future).

Although this study is the first longitudinal study to examine perceived epilepsy-related stigma over time among children with epilepsy and their caregivers, limitations and ideas for future research were noted. This study demonstrated that perceived epilepsy-related stigma decreases over time, but it does not explicitly explore other co-occurring factors that may

contribute to stigma reduction. An important future direction is to assess whether adaptation to medical diagnosis and/or changes in family recreational patterns contribute to stigma reduction. Additionally, this study used a relatively small child sample ($n=39$) who represented children 8–12 years of age. It would be beneficial to examine perceived epilepsy-related stigma and its impact on children and their caregivers with a larger sample size and across a broader developmental cohort (e.g., including adolescents). Another important area to explore is the relationship between perceived stigma and adherence, as the anticipation of judgment from others may negatively impact adherence (e.g., abstaining from AEDs during a sleepover for fear of being teased by a peer). Studying the relationship between perceived stigma and adherence, as well as depression and self-concept will also shed some insight into whether or not perceived stigma negatively impacts children in the same manner as adults. Finally, while this study gathered information regarding seizure status, it did not differentiate between types of seizures. Stigma literature suggests that individuals who experience more visible conditions are more likely to experience stigma than individuals who are able to easily conceal their illness [20]. Thus, future research is needed to determine if perceived epilepsy-related stigma is related to type and/or frequency of seizure(s) so that interventions aimed at ameliorating the effects of stigma can be tailored to fit the specific needs of particular seizure types if indicated.

Acknowledgments

We would like to extend our gratitude to the children with epilepsy and their families who participated in this study. We thank the healthcare team in the New Onset Seizure Clinic for allowing the research to be conducted. We also extend our appreciation to Julie Field for recruiting participants and collecting their perceived stigma data.

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Highlights

- Children with epilepsy experience a decrease in epilepsy-related stigma over time
- Children with and without seizures report comparable levels of stigma
- Children and caregivers have poor agreement on child epilepsy-related stigma

Figure 1.
Observed and model-based caregiver and child stigma scores over a 2-year period

Table 1**Participant Demographics and Medical Variables**

Participant Characteristics	Total Sample (n=97)	Child Sample Only (n=39)
Child Age (years), Mean $\pm$ SD	7.14 $\pm$ 2.87	9.95 $\pm$ 1.40
Child Sex	60.8% male	51.3% male
Child Race (%)		
Caucasian	76	80
African-American	14	8
Bi/Multi-racial	10	12
Seizure Type (%)		
Localization-related	55	54
Generalized	25	33
Unclassified	20	13
Non-convulsive versus Convulsive Seizures (%)		
Non-convulsive	32	33
Convulsive	68	67
Caregiver Age (years), Mean $\pm$ SD	35.63 $\pm$ 6.97	36.47 $\pm$ 4.69
Caregiver Race (%)		
Caucasian	82.5	84.6
African-American	13.4	12.8
Bi/Multi-racial	4.2	2.6
Questionnaires Completed By (%)		
Mother	79.4	71.8
Father	15.5	25.6
Parent jointly	2.1	0
Other	3.1	2.6
Marital Status (%)		
Married	64.9	59.0
Separated/Divorced/Widowed	14.4	23.1
Single	20.6	17.9
Revised Duncan Score, Mean $\pm$ SD	42.81 $\pm$ 22.72	48.91 $\pm$ 20.87

Note: SD=standard deviation; Revised Duncan Score is an occupation based measure of socioeconomic status (SES).