Measuring stigma in children with epilepsy and their parents: instrument development and testing

Joan K. Austin, a,* Jessica MacLeod, a David W. Dunn, b Jianzhao Shen, b and Susan M. Perkins b

a Indiana University School of Nursing, Indianapolis, IN 46202-5107, USA
b Indiana University School of Medicine, Indianapolis, IN 46202-5200, USA

Received 4 March 2004; accepted 21 April 2004
Available online 2 June 2004

Abstract

Purpose. The goal of this work is to describe psychometric properties of two scales measuring perceived stigma in children with epilepsy and their parents.

Methods. Data were collected for the parent scale in two samples: parents of 173 children with epilepsy and of 224 children with new-onset seizures. The child scale was tested in the chronic sample. Content validity, internal consistency reliability, and construct validity were tested.

Results. Both scales had strong internal consistency reliability and construct validity. Higher scores were associated with greater seizure severity scores. In the parent scale, lower scores were associated with more positive mood, less worry, and more family leisure activities. In the child scale, higher scores were correlated with more negative attitude, greater worry, poorer self-concept, and more depression symptoms.

Conclusions. Both scales were found to have strong psychometric properties. They are short, and items are easy to understand. These scales have potential for use in research and in the clinical setting to measure stigma.

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Keywords: Stigma; Instrument development; Parents; Children and adolescents; Epilepsy

1. Introduction

To develop and implement interventions to improve the psychosocial health of people with epilepsy, it is important for researchers and clinicians to understand the effects of the stigma that accompanies this disorder. Even as our understanding of the pathophysiology and treatment of epilepsy improves, the associated stigma continues to cause problems in the lives of those with this common neurological disorder. People with epilepsy report that stigma is one of the greatest challenges that they face [1]. A recent World Health Organization campaign, “Out of the Shadows,” focused attention on the problems caused by the stigma associated with epilepsy [2].

Because the development of self-identity and peer relationships is of critical importance in adolescence, stigma encountered at this particular life stage may greatly influence psychosocial health and self-esteem [3]. A recent, large survey found that teens in the general population held beliefs about people with epilepsy that reflected attitudes of stigma [4]. For example, 40% of the adolescents were not sure if people with epilepsy were dangerous or not, and less than one third (31%) reported that they would date someone with epilepsy [4].

Although stigma is an important factor in the lives of adolescents with epilepsy, it has not been extensively studied and is not yet well understood. Stigma is a complex concept to investigate in this population because it involves personal attitudes and beliefs, elements of secrecy and disclosure management, as well as...
influences from the social environment. Researchers have attempted to measure perceived stigma in people with epilepsy in different ways. Although these studies had limitations, they do provide important information related to the measurement of stigma in adolescents with epilepsy.

One of the earliest studies that measured perceived stigma was by Ryan et al. [5]. As part of a larger study on employment in older adolescents and adults with epilepsy, they administered a questionnaire that measured attitudes related to epilepsy. The authors did not report on how items were developed. A factor analysis of 21 attitude items identified three factors, one of which reflected perceived stigma. Exploration of relationships using path analysis indicated that stigma was positively correlated with seizure severity, perceived discrimination, and perceived limitations. In addition, perceived stigma was negatively correlated with education [5]. Interestingly, most study respondents reported not feeling stigmatized. The validity of the subscale used to measure stigma was supported, and the study may help researchers begin to understand stigma in adolescents with epilepsy. However, this study has limitations. First, the sample was aged 15 or older, and findings may not apply to younger adolescents with epilepsy. Second, the authors themselves noted that the stigma factor was necessarily influenced by the choice of the initial 21 attitude items. A final limitation was the lack of information on how the items were developed, including any ratings of content validity.

Only one study [6] tested a stigma theory in adolescents with epilepsy. They proposed relationships between stigma attributes, management of disclosure, perceived stigma, and self-esteem. The authors’ operational definition of stigma reflected the belief that stigma negatively influenced social relationships. Perceived stigma was measured through four questions that loaded on a single factor using factor analysis. Higher total scores indicated greater perceived stigma. Disclosure management was measured through four questions that also loaded on a single factor, with higher total scores indicating greater concealment of the disease. Results from this study were interesting, but equivocal. The responses to the perceived stigma items showed that most of the adolescents did not feel stigmatized. However, the disclosure management items indicated that most (59%) of the adolescents were not revealing their epilepsy to others and that a large majority (70%) were rarely or never talking about their epilepsy with others [6]. These results emphasize that stigma is complex and may be difficult to measure directly, because adolescents’ statements of not feeling that epilepsy has a stigma are not consistent with their secret-keeping behavior.

A study by Cramer et al. [7] had similar results in that it also failed to demonstrate high levels of perceived stigma. These authors included a stigma subscale in their development of the QOLIE-AD-48, a tool that measures quality of life in adolescents with epilepsy. This scale has demonstrated adequate content and construct validity, as well as reliability [7]. The mean stigma subscale score was 71.3, with a standard deviation of 22.0 and a range from 0 to 100. Higher scores indicated less felt stigma. The adolescents in this study were patients from epilepsy centers in large teaching hospitals. It is possible that these adolescents did not feel a high level of stigma because they received specialized care and support from neurology clinics.

Two studies used a stigma scale developed by Jacoby [8]. On this scale one point is given for a positive response to each of three questions related to stigma, with higher scores indicating greater perceived stigma. The tool, which was originally developed to measure stigma in those with stroke, was revised to be relevant for those with epilepsy for use in this study. In one study [8] only 14% of adolescents and adults with epilepsy age 16 years or older scored even one point on the stigma scale, indicating that they did not feel stigmatized. In this study, the tool had adequate internal consistency reliability, and support for validity was found when a higher stigma score was related to fewer social activities. In contrast, in a study of people with epilepsy in 15 European countries using the same stigma scale [9], most (51%) reported feelings of stigma. Furthermore, 18% scored positively on all three items, indicating they felt highly stigmatized. The population in this study was also aged 16 or older. It is interesting that the same stigma tool produced such disparate results in different geographical areas. This reinforces that stigma is influenced not only by personal attributes, but also by cultural attitudes and beliefs. This brief scale is designed for adults and does not include information on disclosure.

There has been variability in past studies in the informants used to measure stigma in children. For example, Britten et al. [10] attempted to measure stigma in adolescents through teacher reports of extreme behavior. Use of different informants, however, could have affected results, and, in fact, reports of child depression or behavior problems have differed in past research, depending on whether the child with epilepsy or the parent was questioned [11,12]. In the same way, it is likely that feelings of stigma are an individual, subjective experience that are not accurately measured through the perceptions of another.

Perceptions of stigma in adolescents with epilepsy are complex and encompass personal and social factors. Attempts have been made to measure perceived stigma in people with epilepsy; however, the tools used in previous research may be problematic when used with adolescents. Some measurement tools have been tested and validated in older adolescent and adult populations [5,8,9]. Those tested only in adolescent populations have yielded equivocal results [6,7]. Other tools have
measured stigma in adolescents with epilepsy indirectly, through the reports of teachers or parents [10]. To best study the concept of stigma in adolescents with epilepsy, a measurement tool must be developed that is specific to the population, includes perceptions related to both self and others, and includes questions about disclosure. Because the family environment is an important influence on children's perceptions, it is also important to obtain perceptions of stigma from others in the family.

The goal of this study was to test the psychometric properties of two recently developed instruments to measure perceived stigma. One scale was developed to be completed by parents of children and adolescents with epilepsy. The second scale was developed to be completed by adolescents with epilepsy. Our aims were to:

1. Investigate psychometric properties (internal consistency reliability and construct validity) of both stigma scales.
2. Describe relationships of perceived stigma to demographic (parent and child age, gender, and parent education) and seizure (age of seizure onset, duration of disorder, seizure severity, and seizure type) variables for both scales.
3. Test predicted relationships between stigma scores and related constructs. Predicted relationships were:
   (a) Greater perceptions of stigma will be associated, in parents and children, with younger age of onset, greater seizure severity, and less seizure management confidence.
   (b) Greater perceptions of stigma will be associated with more worry related to epilepsy in both children and parents.
   (c) Greater perceptions of stigma will be associated with parent negative mood and more problems in family life/leisure in parents.
   (d) Greater perceptions of stigma will be associated with more negative attitude toward having epilepsy, poorer self-concept, and more symptoms of depression in children.
   (e) There will be a positive correlation between parent and child stigma scores.

2. Instrument development

2.1. Item generation

2.1.1. Parent scale

For the purposes of instrument development we conceptualized stigma as referring to an attribute (i.e., seizure condition) held by a person that leads to his or her being discredited or devalued by others [13]. We began the instrument development for the parent scale in a prior study of children with chronic epilepsy. We conducted a literature search and carried out open-ended interviews with parents of children with chronic epilepsy. The literature was reviewed in the area of stigma related to chronic illness generally, and to epilepsy specifically. In addition, parents of children with chronic epilepsy were interviewed about their concerns, including those related to stigma. In our interviews, parents consistently reported concerns that others held negative views about epilepsy, but that they did not hold these views themselves. As a result of these interviews, we developed parent items that reflect the parents' perceptions of how others might view their child because of the epilepsy.

We found four items on the stigma scale developed by Ryan et al. [5] to have content consistent with our literature search and interviews with parents. We revised these items to be appropriate for parents of children with chronic epilepsy and added two new items. One reflected the concern that parents voiced about their children possibly having trouble finding a marriage partner. We also included an item that referred directly to epilepsy having a stigma or label. This 6-item scale, which had a 7-point response scale, was piloted in the prior study. As a result of this testing, we dropped one item and changed the response scale to a 5-point scale.

For the studies reported here parents were asked to respond to five items (see Table 2) on 5-point scales from 1 (strongly disagree) to 5 (strongly agree). To score, the five items are summed and divided by the number of items. A higher score reflects greater perceptions of stigma associated with their child having epilepsy.

2.1.2. Child scale

Items for the Child Stigma Scale (Table 3) were developed from a review of the literature and open-ended interviews with children with epilepsy about their concerns and fears related to having seizures. Based on these findings we developed items related to feelings of being different and embarrassment because of the seizures. We also phrased the items to reflect the children’s perceptions of how others viewed them if they knew they had a seizure condition. Specifically, we asked children to report how often they felt or did not want to be their friend because of the epilepsy. Finally, items were developed related to disclosure (i.e., keeping the seizure condition a secret and avoiding talking about their seizure condition).

The children were asked to rate how often they felt or acted in the ways described in the items on 5-point scales from 1 (never) to 5 (very often). To score, the items were summed and divided by the number of items. A higher score reflects greater perceptions of stigma.

2.1.3. Expert evaluation

Prior to this study, each of the scales was reviewed by five content experts. These experts were professionals from medical, psychology, and public health
backdrops with expertise in measurement of attitudes and perceptions related to epilepsy. Reviewers were asked to provide feedback on each item for its relevance to the construct of stigma as it applied to having epilepsy. They also were asked to evaluate the instructions and response scales. Finally, for the child scale they were asked to evaluate the readability and appropriateness of the items for children aged 9 or older. Revisions were made based on their evaluation of the scale.

3. Studies of psychometric properties

For the parent scale psychometric properties were studied in two different samples: parents of children with chronic epilepsy and new-onset seizures. Psychometric properties of the child scale were investigated only in the chronic sample.

3.1. Chronic sample

3.1.1. Participants

Participants were 173 children (85 girls, 88 boys) aged 9 to 14 years and their major caregiving parent. The mean child age was 11.8 years. With few exceptions, the major caregiver was the mother. The large majority (91%) of the sample was Caucasian, 6% were African–American, and 3% were other. On average, the children’s primary caregiver had more than a high school education.

Children were recruited from clinics, schools, and private practices of pediatric neurologists in a large Midwestern city. All children had been prescribed anti-epileptic medication and had a definitive diagnosis of epilepsy. Exclusion criteria were diagnosis of mental retardation, another major chronic physical disorder, or a progressive brain disorder. Seizure data were obtained from parent interview and clinical records. The average duration of the disorder in the sample was slightly over 5 years (mean = 5.18, SD = 3.83). See Table 1 for additional information on the sample. The parent stigma scale was completed by 171 parents and the child stigma scale was completed by 170 children (99 and 98% of the sample, respectively).

3.1.2. Procedures

The study was approved by the university institutional review board. Informed consent was obtained from parents and informed assent from children before data collection. Data were collected using computer-assisted telephone interviews as part of an ongoing longitudinal study of adjustment in children with chronic epilepsy. Baseline data were used for this study.

3.2. New-onset sample

3.2.1. Participants

Participants were 224 parents of children (116 girls, 108 boys) aged 4 to 14 years. The mean child age was 8.5 years (SD = 3.0). At enrollment the children were within 6 weeks (mean = 35 days) of their first recognized seizure. The racial distribution for the children was: Caucasian (75%), African–American (22%), and other (3%). On average, the parent had more than a high school education (mean = 13.8 years, SD = 2.6). With few exceptions, the major caregiver was the mother.

Subjects were recruited through electroencephalogram (EEG) laboratories, emergency departments, and pediatric neurologists in two large children’s hospitals (Indianapolis and Memphis) and from practices of private pediatric neurologists in Indianapolis. Exclusion criteria were: a comorbid chronic physical disorder, mental retardation, and seizures precipitated by an acute event (e.g., intracranial infection, metabolic derangement, recent head injury). Children were also excluded if they had had two or more febrile seizures or had re-

<table>
<thead>
<tr>
<th>Characteristics of samples</th>
<th>Chronic sample (N = 173)</th>
<th>New-onset sample (N = 224)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Caregiver</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>38.8</td>
<td>5.6</td>
</tr>
<tr>
<td>Education</td>
<td>13.5</td>
<td>2.3</td>
</tr>
<tr>
<td>Child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>11.8</td>
<td>1.8</td>
</tr>
<tr>
<td>Gender (% female)</td>
<td>51.0</td>
<td></td>
</tr>
<tr>
<td>Age at seizure onset</td>
<td>6.5</td>
<td>3.8</td>
</tr>
<tr>
<td>Main seizure type (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>17.3</td>
<td></td>
</tr>
<tr>
<td>Partial without generalization</td>
<td>39.9</td>
<td></td>
</tr>
<tr>
<td>Partial with generalization</td>
<td>19.1</td>
<td></td>
</tr>
<tr>
<td>Generalized tonic–clonic and AAM†</td>
<td>20.8</td>
<td></td>
</tr>
<tr>
<td>Unclassified</td>
<td>2.9</td>
<td></td>
</tr>
</tbody>
</table>

†AAM: atonic, akinetic motor.
ceived treatment for any febrile seizure. See Table 1 for additional information on the sample.

3.2.2. Procedures

The study was approved by the university institutional review board. Informed consent was obtained from parents prior to data collection. Data were collected using computer-assisted telephone interviews as part of a larger prospective study of behavior problems in children with new-onset seizures. Data collected at 3 months after the first recognized seizure were used for this study. The parent stigma scale was completed by 210 parents (94% of the sample).

4. Measurement

4.1. Demographic variables

Demographic variables explored for relationships with perceived stigma were caregiver and child age, child gender, and number of years of caregiver education. All demographic variables were based on parent report. Parent age was calculated by subtracting the date of the interview from the parent's date of birth. To obtain the child's age, date of birth was subtracted from the date of the interview. Caregiver education was measured to the nearest year.

4.2. Seizure variables

Aspects of the seizure condition measured were: age of onset, duration, seizure type, and seizure severity. The child’s age of seizure onset was determined by parent report. Duration of the seizure disorder was calculated by subtracting the date of seizure onset from the date of the interview. Seizure type was determined by author D.W.D. using information from the clinical records and the caregiver’s description of the seizures. For analysis, seizures were placed into four categories: generalized absence, generalized tonic-clonic, partial without generalization, and partial with generalization.

Seizure severity was measured by revising a Seizure Severity Scale for adults [14]. This scale reflects the degree to which seizures disrupt everyday life for adults and the extent of the seizures. The scale was revised by the current authors (with consultation from the developers) for parents to complete and describe their child's seizure condition. On this 9-item scale, items are given weights from 0 to 3. Items reflect intrusiveness of the seizure (e.g., incontinence, loss of consciousness), disruptiveness of the seizure (e.g., bizarre movements, undressing self), and effects of the seizure (e.g., injury, confusion, sleepiness). These items are rated as follows: 0 (never), 1 (sometimes), 2 (usually), and 3 (always). Other items measure time of disruption. Seizure length was coded as follows: 0 (less than 1 minute), 1 (between 1 and 2 minutes), 2 (between 2 and 5 minutes), and 3 (more than 5 minutes). Time until resuming normal activities after the seizure is coded as follows: 0 (less than 1 minute), 1 (between 1 and 5 minutes), 2 (between 5 minutes and 1 hour), and 3 (more than 1 hour). Parents completed the scale once for each kind of seizure observed. For children with multiple kinds of seizures, the maximum score was used in analysis. The internal consistency reliability was 0.79 for the chronic sample.

4.3. Parent measures

4.3.1. Confidence in seizure management

A scale to measure parents’ perceptions of their ability to manage their child’s seizure condition was developed by the authors. The scale has five items related to how confident the parent feels about handling the child’s seizures, including items related to calling the doctor, recognizing side effects of medication, taking the child to the emergency room, and handling the next seizure. Parents respond with how much they agree with items on 5-point scales from 1 (strongly disagree) to 5 (strongly agree). For scoring, items are summed and divided by 5 to obtain a mean score. A higher score reflects greater parent confidence. The internal consistency reliability was 0.72 for the chronic sample and 0.66 for the new-onset sample.

4.3.2. Worry

Parent worry was measured using the Parent Need for Psychosocial Care [15]. The Parent Worry subscale consists of five items related to perceptions of possible causes of their child’s seizures (e.g., brain tumor) and common worries about the negative effects of their child’s seizures (e.g., brain damage). Parents responded on 4-point scales: 1 (not at all), 2 (somewhat), 3 (moderately), and 4 (very much). For scoring, items were summed and divided by the number of items, with a higher score reflecting more worry. The internal consistency reliability was 0.81 for the chronic sample and 0.82 for the new-onset sample.

4.3.3. Positive mood

Parent mood was measured by asking parents to think about how they felt being a parent of a child with a seizure condition. They were then asked to describe the extent to which they experienced each of eight feeling adjectives (sad/gloomy, calm/relaxed, tense/fearful, angry/irritated, guilty/blamed, frustrated/exasperated, worried/nervous, and tired/spent). Parents responded on 7-point scales of 1 (do not feel at all) to 7 (feel very much). For scoring, scores were reversed for negative adjectives and an average score was derived. The internal consistency reliability was 0.87 for the chronic sample and 0.86 for the new-onset sample.
4.3.4. Family life/leisure

A scale to measure impact of the seizures on family life and family participation in leisure activities outside the home was developed by the authors. The scale has 10 items. Seven items relate to how seizures might influence family participation in activities, two items relate to parent agreement related to handling the child’s seizure condition, and one item asks about the effect of the seizure condition on other children. Parents respond with how much they agree with items on 5-point scales from 1 (strongly disagree) to 5 (strongly agree). For scoring, items are summed and divided by 10 to obtain a mean score. A higher score reflects greater family participation in leisure activity and lower impact of the seizures on family life. The internal consistency reliability was 0.89 for the chronic sample and 0.86 for the new-onset sample.

4.4. Child variables

4.4.1. Confidence in seizure management

Child seizure management was measured using the Seizure Self-Efficacy Scale for Children (SSES-C), [16] a 15-item scale that measures the degree of self-efficacy related to the management of the seizure disorder. The children rated each statement on a 5-point scale of 1 (I’m very unsure I can do that) to 5 (I’m very sure I can do that). A mean score was obtained by summing across all items and dividing by the number of items. A higher score reflects greater self-efficacy. Support for reliability and validity has been reported [16]. A higher score on Seizure Management reflects greater child confidence in the ability to handle his or her seizure condition. The internal consistency reliability was 0.93 in the chronic sample.

4.4.2. Worry

Child worry was measured using 13 items that ask children how often they worry about particular aspects of having epilepsy. The items on this scale were obtained in past research from open-ended interviews with children [17]. Areas of worry or concern addressed in the scale include causes of seizures, being alone in case of a seizure, getting blood tests, getting hurt during a seizure, and not being able to do some things because of the seizures. Children responded on 5-point scales of 1 (never) to 5 (very often), with a higher mean score reflecting greater worry. The internal consistency reliability was 0.84 in the chronic sample.

4.4.3. Child attitude toward epilepsy

Attitude was measured by the Child Attitude Toward Illness Scale (CATIS) [18]. The CATIS is a 13-item scale that measures, along one dimension, children’s positive and negative feelings about having a seizure condition. It has had good reliability and validity in past studies [18,19]. The possible range of mean scores is 1–5, with scores of 1 and 2 indicating negative feelings, 3 being neutral, and 4 and 5 indicating positive feelings. The internal consistency reliability was 0.78 in the chronic sample.

4.4.4. Self-concept

Self-concept was measured using the Piers–Harris Child Self-Concept Scale [20]. The CSCS is an 80-item scale that measures children’s perceptions of themselves. The scale is scored so that higher scores reflect more positive self-concept. Past research by the authors has supported the reliability and validity of the instrument. The coefficient α for the total score was 0.91 in the chronic sample.

4.4.5. Depression symptoms

Symptoms of depression were measured using the Child Depression Inventory (CDI) [21]. The CDI is a 27-item scale that measures overt symptoms of depression. A higher score reflects more symptoms of depression. Support for reliability and validity of the CDI has been found in previous research [21]. The coefficient α for child depression was 0.83 in the chronic sample.

5. Data analyses

Item distributions were explored to check item variability. Exploratory factor analysis was next carried out to identify how many factors were hidden within the scale. The principal factor method was used to extract the factors, and the prior commonalities were estimated using squared multiple correlations. Dimensionality for each of the two scales was determined using eigenvalues, scree plots, and magnitude of factor loadings, as each scale has a relatively small number of items. Finally, the coefficient αs were calculated to test internal consistency reliability and validity. Pearson correlation coefficients were calculated to check relationships with demographic variables and other related constructs.

6. Results

6.1. Psychometric properties

6.1.1. Parent scale

All items had acceptable variability, with standard deviations, ranging from 0.93 to 1.16 for the chronic sample and from 1.54 to 2.07 for the new-onset sample. Factor analysis showed that one factor alone accounted for 100% of common variance for both samples and 55% and 54% of total variances, respectively, for the chronic and new-onset samples. Factor loadings for items ranged from 0.69 to 0.84 for the chronic sample and
from 0.63 to 0.82 for the new-onset sample. The scree plots for both samples showed the eigenvalues decreased in a flat gradual way after the first factor. The consistently high factor loadings and flat scree plot after the first factor strongly supported one unitary construct of the scales. The coefficient $z$ were 0.79 and 0.77 for the chronic and new-onset samples, respectively. Corrected item-to-total correlations ranged from 0.52 to 0.70 in the chronic sample and from 0.50 to 0.64 in the new-onset sample (see Table 2).

### 6.2.2. Child scale

The child scale was only administered to the chronic sample. Items had acceptable variability, with standard deviations ranging from 1.24 to 1.54. Initial exploration using factor analysis and item-to-total correlations indicated that two items should be dropped. After these items were dropped, one factor alone accounted for 100% of common variance and 44% of the total variance. In addition, factor loadings ranged from 0.56 to 0.77. The scree plot showed the eigenvalues decreased in a flat gradual way after the first factor. The consistently high factor loadings and flat scree plot after the first factor strongly supported one unitary construct of the scales. The coefficient $z$ was 0.81. Corrected item-to-total correlations ranged from 0.44 to 0.65 for the child scale (see Table 3).

### 6.2. Relationships with demographic and seizure variables

#### 6.2.1. Parent scale

The scales' mean scores (chronic sample: $M = 2.58$, $SD = 0.81$; new-onset sample: $M = 2.67$, $SD = 1.28$) indicate a neutral perception of stigma on average. Although the mean for stigma in the new-onset sample is slightly higher than for the chronic sample, the results do not approach significance. Correlations of stigma with demographic, seizure, child, and family variables are listed in Table 4. There were no associations between parent stigma scores and parent education for either sample. In addition, there were no significant differences between parents of boys (chronic sample: $M = 2.55$, $SD = 0.80$; new-onset sample: $M = 2.65$, $SD = 1.29$) and parents of girls (chronic sample: $M = 2.62$, $SD = 0.83$; new-onset sample: $M = 2.68$, $SD = 1.28$). In the chronic sample, younger child and parent ages were associated with greater perceptions of stigma; these correlations were not found in the new-onset sample. With regard to seizure type, significant mean differences were found for the chronic sample ($P < 0.05$) but not the new-onset sample. In the chronic sample, pairwise comparisons by seizure type using Tukey–Kramer adjustment found a difference between parents of children with absence and partial with generalization seizures (absence: $M = 2.27$, $SD = 0.82$; partial with generalization: $M = 2.87$, $SD = 0.81$). There was no association with duration of epilepsy in the chronic sample.

#### 6.2.2. Child scale

The mean child response for perceived stigma was between “sometimes” and “often” ($M = 2.24$, $SD = 0.88$). There was no difference in scores between boys ($M = 2.17$, $SD = 0.89$) and girls ($M = 2.32$, $SD = 0.86$), nor was there an association between stigma scores and parent education level. As expected, the correlation between the child stigma score and the parent stigma score was significant, though it was not strong ($r = 0.30$, $P < 0.001$). Younger child age was associated with greater perceptions of stigma ($r = -0.22$, $P < 0.01$). Although younger age of onset of epilepsy also was

### Table 2

<table>
<thead>
<tr>
<th>Item</th>
<th>Chronic sample ($n = 171$)</th>
<th>New-onset sample ($n = 210$)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$M$</td>
<td>SD</td>
</tr>
<tr>
<td>People who know that____ has a seizure condition treat him/her differently.</td>
<td>2.65</td>
<td>1.13</td>
</tr>
<tr>
<td>It really doesn’t matter what I say to people about____’s seizure condition, they usually have their minds made up.</td>
<td>2.68</td>
<td>1.13</td>
</tr>
<tr>
<td>____ always has to prove him/herself because of the seizure condition.</td>
<td>2.33</td>
<td>1.13</td>
</tr>
<tr>
<td>Because of the seizure condition, ____ will have problems in finding a husband or wife.</td>
<td>1.98</td>
<td>0.93</td>
</tr>
<tr>
<td>In many people’s minds, a seizure condition attaches a stigma or label to _____.</td>
<td>3.28</td>
<td>1.16</td>
</tr>
<tr>
<td>Total score</td>
<td>2.58</td>
<td>0.81</td>
</tr>
</tbody>
</table>

Note. Rating scale: 1 = strongly disagree, 2 = disagree, 3 = neither, 4 = agree, 5 = strongly agree.
6.3. Correlations with child and family variables

6.3.1. Parent scale

Table 4 also lists Pearson correlation coefficients between parent and child stigma scores and child and family variables. As hypothesized, for the chronic sample, greater perceptions of stigma were associated with greater seizure severity ($r = 0.29, P < 0.01$) and less seizure management confidence ($r = -0.23, P = 0.01$). Seizure management confidence was not associated with stigma scores in the new-onset sample. In both samples, higher stigma scores were associated with more worry, more parent negative mood, and more negative impact of epilepsy on family life and leisure.

### Table 3
Child stigma scale ($n = 170$)

<table>
<thead>
<tr>
<th>Item</th>
<th>$M$</th>
<th>SD</th>
<th>Item-total correlation</th>
<th>Factor loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often do you feel different from other kids because you have a seizure condition?</td>
<td>2.17</td>
<td>1.27</td>
<td>0.50</td>
<td>0.63</td>
</tr>
<tr>
<td>How often do you feel people may not like you if they know you have a seizure condition?</td>
<td>2.15</td>
<td>1.28</td>
<td>0.55</td>
<td>0.69</td>
</tr>
<tr>
<td>How often do you feel other children are uncomfortable with you because of your seizure condition?</td>
<td>2.20</td>
<td>1.30</td>
<td>0.53</td>
<td>0.68</td>
</tr>
<tr>
<td>How often do you feel people may not want to be friends with you if they know you have a seizure condition?</td>
<td>1.97</td>
<td>1.24</td>
<td>0.65</td>
<td>0.77</td>
</tr>
<tr>
<td>How often do you feel people would not want to go out with you or ask you to parties if they know you have seizures?</td>
<td>2.05</td>
<td>1.28</td>
<td>0.59</td>
<td>0.74</td>
</tr>
<tr>
<td>How often do you feel embarrassed about your seizure condition?</td>
<td>2.11</td>
<td>1.27</td>
<td>0.53</td>
<td>0.64</td>
</tr>
<tr>
<td>How often do you keep your seizure condition a secret from other kids?</td>
<td>2.60</td>
<td>1.54</td>
<td>0.46</td>
<td>0.58</td>
</tr>
<tr>
<td>How often do you try to avoid talking to other people about your seizure condition?</td>
<td>2.70</td>
<td>1.44</td>
<td>0.44</td>
<td>0.56</td>
</tr>
<tr>
<td>Total score</td>
<td>2.24</td>
<td>0.88</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* Rating scale: 1 = never, 2 = not often, 3 = sometimes, 4 = often, 5 = very often.

### Table 4
Correlations of stigma scores with demographic, seizure, child, and family variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Parent scale</th>
<th>Child scale</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>New-onset</td>
<td>Chronic</td>
</tr>
<tr>
<td>Demographic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child age (at 3 months)</td>
<td>-0.02</td>
<td>-0.12</td>
</tr>
<tr>
<td>Parent age</td>
<td>-0.10</td>
<td>-0.22**</td>
</tr>
<tr>
<td>Parent education</td>
<td>0.04</td>
<td>-0.04</td>
</tr>
<tr>
<td>Seizure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of seizure onset</td>
<td></td>
<td>-0.19*</td>
</tr>
<tr>
<td>Duration of seizure disorder</td>
<td></td>
<td>0.12</td>
</tr>
<tr>
<td>Seizure severity</td>
<td></td>
<td>0.29***</td>
</tr>
<tr>
<td>Child and family variables</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confidence in seizure management</td>
<td>-0.08</td>
<td>-0.23**</td>
</tr>
<tr>
<td>Worry</td>
<td>0.25***</td>
<td>0.37***</td>
</tr>
<tr>
<td>Positive mood</td>
<td>-0.31***</td>
<td>-0.38***</td>
</tr>
<tr>
<td>Family life/leisure</td>
<td>-0.42***</td>
<td>-0.45***</td>
</tr>
<tr>
<td>Attitude</td>
<td></td>
<td>-0.60***</td>
</tr>
<tr>
<td>Self-concept</td>
<td></td>
<td>-0.38***</td>
</tr>
<tr>
<td>Depression symptoms</td>
<td></td>
<td>0.48***</td>
</tr>
</tbody>
</table>

$^1 P < 0.05$.  
$^* P < 0.01$.  
$^** P < 0.001$.  

Associated with greater stigma ($r = -0.17$), duration of seizure condition was not. No differences in stigma scores were found by seizure type.

6.3. Correlations with child and family variables

6.3.2. Child scale

As hypothesized, greater perceptions of stigma were associated with greater seizure severity ($r = 0.24, P < 0.01$) and less seizure management confidence ($r = -0.27, P < 0.01$). The more worry related to having epilepsy, the greater the child’s perceptions of stigma ($r = 0.52, P < 0.0001$). Children with higher stigma scores had more negative attitudes toward having epilepsy, poorer self-concepts, and more symptoms of depression ($r = -0.60, -0.38, and 0.48$, respectively, $P < 0.0001$ for all three).
7. Discussion

The purpose of this study was to evaluate two new instruments designed to measure perceptions of stigma in children with epilepsy and their parents. Results suggest that both stigma instruments are unidimensional scales that have satisfactory content validity, high internal consistency reliability, and satisfactory construct validity. Empirical support for the predicted relationships between stigma perceptions and key seizure, child, and family variables also provides evidence for the validity of both scales. The expected positive correlation between parent and child stigma scores was supported. In addition, for both scales the predicted associations between greater perceptions of stigma and greater worry were empirically supported. This latter finding is consistent with the literature showing relationships between stigma and worry in studies of adults [8,9]. In addition, the anticipated relationship between greater perceptions of stigma and higher seizure severity was supported for both scales in the chronic sample. This finding is consistent with other studies of persons with chronic epilepsy [5,9]. Other findings are discussed for parent and child scales separately.

7.1. Parent scale

Of the two scales the parent stigma scale is more developed. It had strong construct validity and internal consistency reliability in both parent samples. Moreover, there were no differences in stigma based on child gender or parent education in either sample. In addition, with few exceptions, the predicted associations with other variables had empirical support. The relationship between greater parent perceptions of stigma and a more negative effect on family life had the strongest associations in both samples. We had hypothesized that parents who perceived reactions of others to be negative would limit the possible exposure of their child’s seizures to others by limiting family activities. This finding is consistent with the study by Jacoby [8], who found a relationship between greater perceptions of stigma and social isolation in adults. In addition, the association between negative mood and greater perceptions of stigma found in this study is also consistent with the literature [22].

Expected correlations between stigma scores and other variables were not always found for both samples. In the chronic sample, younger child age of seizure onset and younger parent age were both associated with greater perceptions of stigma, but these correlations were not found in the new-onset sample. We suspect that the relationship between age of onset and greater perceptions of stigma in the chronic sample is related to the fact that seizures that occur earlier in life are often more severe and that the severity of the seizures accounts for the relationship [23]. Although the chronic sample included children with seizures that had begun as early as birth, the new-onset sample limited the lowest age of onset to 4 years. The difference in correlation between parents’ confidence in seizure management was most likely due to the new-onset sample’s lack of experience with managing their child’s seizures. A large proportion of the children in the new-onset sample had had one only seizure so their parents had little opportunity to build confidence.

7.2. Child scale

In addition to good content validity and internal consistency reliability for the child scale, empirical support was found for all predicted relationships with other variables. The predicted association between perception of stigma and attitude toward having epilepsy was strongly supported. Moreover, the associations between greater perceptions of stigma and, respectively, more worry and lower levels of self-efficacy for seizure management also support the validity of the child scale. The final support for validity was the strong association between greater perceptions of stigma and poor mental health. Consistent with other studies finding relationships between perceptions of stigma and low self-esteem [6,8,9], both poorer self-concept and more symptoms of depression in this study were associated with higher levels of perceived stigma in the children with chronic epilepsy. These findings suggest that children who have stronger perceptions of stigma might also be experiencing more mental health problems.

An exploration of relationships with demographic variables indicated that younger child age was associated with greater perceptions of stigma, a finding also reported by Westbrook et al. [6]. No differences were found for child gender or parent education. Finally, the low to moderate correlation between child and parent perceptions of stigma was similar to the magnitude of the association we found between parent and child ratings of the child behavior in our past research [12]. This finding reflects the importance of the family environment to the development of child perceptions. In addition, this relatively low association shows how important it is to measure stigma in both parents and children.

7.3. Implications for research

This study is important for research in children with epilepsy and their parents. Although stigma has been shown to be problematic for children and adolescents with epilepsy, there have previously not been brief scales with good psychometric properties available to measure stigma. It appears from the initial testing of these scales that they will be useful to help researchers assess
perceptions of stigma in children and adolescents with epilepsy and their parents. These scales could prove helpful as we increase our understanding of the relationship between perceptions of stigma and mental health adjustment.

7.4. Implications for practice

Both scales have potential to be useful in clinical practice. The scales were simple to administer in the structured telephone interview format. Children were provided with a copy of the 5-point rating scale so they could refer to it during the telephone interview. Children did not have problems understanding the items or selecting a response on the rating scale. Knowledge about perceptions of stigma is important clinically for designing interventions to enhance psychosocial adjustment to epilepsy. The associations between child perceptions of stigma and, respectively, self-concept and symptoms of depression found in this study also indicate that addressing perceptions of stigma has the potential to improve mental health outcomes. In addition, the scales may be useful clinically to assist in individualizing patient support and care.

7.5. Limitations

One limitation of this study is that test–retest reliability was not explored for either of the instruments. In future research this factor should be determined. Another limitation was that few ethnic minorities were included in the chronic sample, making it difficult to explore differences based on ethnicity and cultural factors. Related to this, the generalizability of the findings in the chronic sample was limited to Caucasians.

8. Conclusion

Our results suggest that both stigma scales are promising. They should be easy for children and parents to complete in the clinical setting, and initial assessment shows that both have good reliability and validity. If future research indicates that these scales are sensitive to change, they could be used to measure change in perceptions of stigma, possibly as the result of particular treatments or interventions. Finally, the scales could potentially be used as clinical and research tools to identify factors that are associated with successful adjustment of children with a seizure disorder over time.

Acknowledgments

This research was supported by Grants NS22416 from the National Institute of Neurological Disorders and Stroke and NR04536 from the National Institute of Nursing Research to J.K.A. We acknowledge assistance from B. Garg, O. Markand, as well as the Epilepsy and Pediatric Neurology Clinics at Riley Hospital, Indiana University Medical Center, Indianapolis, IN. We thank A.M. McNelis and C.P. Shore for help with data collection, P. Dexter for editorial comments, and C. Benson and J. Critchfield for editorial assistance.

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