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DEVELOPMENT OF THE PARENT RESPONSE TO CHILD ILLNESS (PRCI) SCALE

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Abstract

The aims of this study were to develop an instrument to measure parents' responses and perceptions related to the onset of either seizures or asthma in a child (ages 4 to 14 years) and to assess the initial reliability and validity of the instrument. A 35-item scale was developed with five subscales: Child Support (CS), Family Life/Leisure (FL), Condition Management (CM), Child Autonomy (CA), and Child Discipline (CD). Subjects were parents of 224 children with a new-onset seizure and 104 parents of children with new-onset asthma. Internal consistency reliabilities were stronger for CS, FL, and CM than for CA and CD for both samples. Test-retest reliability ranged from good to fair for both samples. The associations between parent positive mood and all of the subscales for both samples in the predicted directions provided key empirical support for validity. The scale has potential for use in research and in the clinical setting. In addition, the scale has potential to be used with other conditions.

Keywords

Instrument development; parent response; child illness; epilepsy; asthma; reliability; validity

Introduction

The onset of a chronic illness such as epilepsy or asthma in a child can increase the challenges of parenting. In addition to helping their child meet normal developmental tasks of childhood, parents need to learn how to manage the condition, to help their child adjust to having a chronic disorder, and to maintain an adaptive family environment. Parents of children with epilepsy have many fears and concerns [1,2], which can negatively affect parenting perceptions and behaviors related to their child's epilepsy and, in turn, can increase the potential for poor child adaptation to epilepsy. In two recent reviews of the literature, family variables were strongly associated with child mental health functioning [3,4]. Because children with epilepsy have high rates of mental health problems and these problems [5–7] have been found very early in the course of the disorder [8], it is especially important that we understand parents' responses to seizures in their children so we can develop interventions to help these families.

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The literature documents that negative parental perceptions and behaviors are related to more behavior problems in children with epilepsy. Parenting variables associated with poorer adaptation in children included negative perceptions about the epilepsy [9–11], negative parent-child interactions and relationships [3,12], and negative expressed emotion [13]. In a longitudinal study investigating parenting when a child was newly diagnosed with epilepsy almost half (48%) of parents were found to be “thrown off balance” by the onset of epilepsy, which in turn, led to fear-related overprotection by parents [14]. In another study mothers who expressed more anxiety about their child’s seizure disorder were more likely to engage in overprotective parenting behaviors and less likely to support the independence of their child [15].

Although most of the instruments measuring family and parenting variables in the literature are well developed and some were developed for families of children with a chronic physical disorder, no instrument could be found that specifically measured parents’ behaviors and perceptions related to parenting the child with new-onset seizures or asthma. The *Parent Response to Child Illness (PRCI) Scale* to address this gap.

It is the purpose of this paper to report on the development of a new instrument that was designed to measure parent perceptions and behaviors when a child has a recent-onset health condition. We report on instrument development, underlying factor structure, and testing of psychometric properties for a sample of children with either new-onset seizures or asthma. Following this we also briefly report on findings from the use of the PRCI with parents of children with chronic epilepsy.

Methods

Instrument Development

Content for items was developed based on a review of the literature related to parenting a child with a chronic illness, including those focusing on parent-child interaction, family maintenance, parent engagement with the child, parent emotional support of the child, parent competence in management of the child’s behavior, and parent protection and indulgence of the child. Items were also generated from open-ended interviews with parents of children with new-onset seizures that focused on their worries and concerns about parenting a child with a new-onset seizure condition and on areas in which they felt they needed assistance related to management of the seizures. Instrument items were designed to reflect the parent’s behaviors, feelings, and perceptions about the child, parenting the child, managing the health condition, and the life of the family. To make the instrument relevant for children with new-onset asthma, we interviewed three clinical nurse specialists who practiced in pediatric asthma clinics about parent responses to asthma onset. Items were selected that were relevant for both conditions and were written in such a manner that words could be substituted to reflect the specific health condition (seizure or asthma) and specific symptoms. Finally, because we planned to administer the instrument using structured telephone interviews, we designed the items so that the child’s first name could be inserted into the scale as it was read to the parent.

A total of 38 items was generated for potential inclusion in PRCI. Items were revised based on recommendations by five experts (three nurses, two psychologists, and one child psychiatrist) with expertise in families and childhood epilepsy and five experts (three nurses and two physicians) with expertise in families and childhood asthma. The response format selected for the instrument was a 5-point scale: *Strongly Disagree*, *Disagree*, *Not Sure*, *Agree*, and *Strongly Agree*.

Underlying Factor Structure

Sample—The PRCI was developed for use in a large longitudinal study investigating child and family adaptation to new-onset seizures or asthma. Children were ages 4 to 14 years at entry into the larger study with either new-onset seizures or asthma within the past 3 months (median = 34 days). Participants were parents of 224 children (116 girls and 108 boys) with a new-onset seizure and 104 parents of children (53 girls and 51 boys) with new-onset asthma. For the seizure sample the mean child age was 8.4 years ($SD = 3.0$) and the racial distribution was: Caucasian (75%), African-American (22%), and other (3%). For the asthma sample the mean child age was 8.0 years ($SD = 2.9$) and the racial distribution was: Caucasian (71%), African-American (22%), and other (7%). On average, parents in both samples had greater than a high school education (epilepsy mean = 13.4 years asthma mean = 13.8 years). With few exceptions, the major caregiver was the mother in both samples.

The seizure sample was 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. All children had experienced a new-onset first recognized seizure. There were children with a history of a prior event that, retrospectively, were probably unrecognized or undiagnosed seizures. These children were also included in the new-onset sample. Exclusion criteria for children with seizures were: a co-morbid chronic physical disorder, mental retardation, or seizures precipitated by an acute event (e.g., intracranial infection, metabolic derangement, or recent head injury). Children were also excluded if they had had two febrile seizures or had received treatment for any febrile seizure. The asthma sample was recruited through asthma and pediatric clinics in the same two hospitals and from private pediatricians. Because we wanted children with asthma who were at the beginning of what appeared to be chronic asthma, we included children with a new diagnosis of asthma or an indication that the asthma symptoms had recently become more severe (e.g., first hospitalization, first emergency room visit, or first referral to an asthma specialist). Exclusion criteria for children with asthma were a co-morbid chronic physical disorder, mental retardation, a previous diagnosis of asthma, or previous long-term treatment for asthma symptoms.

As part of the larger study the PRCI was administered five times: baseline, 3 months, 6 months, 12 months, and 24 months after baseline. Data from the administration of the scales to both samples at 3 months after illness onset were used to determine the underlying factor structure and both 3 months and 6 months were used to evaluate psychometric properties of the instrument. Children who had complete data at both 3 and 6 months were 203 children with a seizure and 87 children with asthma. The study was approved by the Institutional Review Board of Indiana University and the IRB of each of the participating hospitals. In addition, parents signed informed consents prior to data collection. Data were collected using computer-assisted structured telephone interviews.

Data Analysis and Results—Exploratory factor analysis was performed using the 3-month data to explore the number of factors hidden within the scale. Principal axis factoring was used to extract the factors and the prior commonalities were estimated using squared multiple correlations. The promax rotation method was used. The scree plot, eigenvalues, and magnitude of factor loadings were used to determine the number of factors. The factor analysis initially included the 32 items that applied to all children. Omitted from the initial factor analysis were questions that only related to children with two parents (4 items), to children with siblings (1 item), or to children taking a medication (1 item) because including these items reduced our sample size by fifty percent.

Five factors were identified: Child Support, Family Life/Leisure, Condition Management, Child Autonomy, and Child Discipline. The six omitted items were then entered into the factor

analysis to insure that the factors remained stable and to obtain factor loadings for all items. To determine placement into factors for the six items that did not apply to all children, the final factor analysis results were considered, as well as both the theoretical rationale and the strength of the correlation between each of the six items and each of the five subscale scores. Cronbach's alphas and item-to-total correlations were calculated for each of the factors. Two items were dropped from the scale because of low item-to-total correlation and one item was dropped because of lack of theoretical justification. The final scale contains 35 items. Subscale scores were calculated as the mean of all items in each factor and have a potential range from 1.0 to 5.0.

The Child Support factor contains eight items and mean parent ratings for individual items on this scale were relatively high, ranging from 4.02 to 4.76. A higher score on the Child Support subscale reflects greater parent provision of emotional support to the child related to the seizure condition. Average ratings on the ten items on the Family Life/Leisure subscale were also relatively high (3.95 to 4.44). A higher score on this subscale reflects greater family participation in leisure activities. Average ratings on the five items on the Condition Management subscale ranged between 3.75 and 4.22. A higher score on this subscale reflects greater parental confidence that they know how to manage their child's seizure condition. The Child Autonomy subscale contains six items with mean ratings that were closer to the mean (2.32 and 3.87). A higher score on the Child Autonomy subscale reflects more parent encouragement of their child's independence. The Child Discipline subscale contains six items that had average ratings ranging between the mean and slightly above (2.79 and 4.03). A higher score on Child Discipline subscale reflects greater parental confidence in their ability to manage their child's behavior.

Psychometric Properties

Reliability—Two measures of reliability were obtained: internal consistency reliability and test-retest reliability. Internal consistency reliability was tested using coefficient alpha. Data from the 3-month data collection were used to test internal consistency reliabilities. Coefficient alphas for the both samples together were: Child Support (.75), Family Life/Leisure (.87), Condition Management (.77), Child Autonomy (.64), and Child Discipline (.76). The coefficient alphas for the seizure sample were: Child Support (.76), Family Life/Leisure (.85), Condition Management (.72), Child Autonomy (.67), and Child Discipline (.70). Although the reliability is only fair for Child Autonomy, the other subscales had good internal consistency reliability. When the internal consistency reliabilities were investigated for the asthma sample, results were similar with the exception of Autonomy and Discipline: Child Support (.72), Family Life/Leisure (.89), Condition Management (.84), Child Autonomy (.57), and Child Discipline (.59). The internal consistency reliability for the Child Autonomy and Discipline factors were low for the asthma sample.

To obtain an estimate of test-retest reliability, data from the 3-month and 6-month data collections were explored for stability by calculating intraclass correlation coefficients. We hypothesized that this 3-month period would be a relatively stable one especially in relation to parent-child interactions. Intraclass correlation coefficients for the seizure sample were: Child Support (.62), Family Life/Leisure (.47), Condition Management (.51), Child Autonomy (.72), and Child Discipline (.71). Three of the factors (Child Support, Child Autonomy, and Child Discipline) had coefficients in the "good" range (i.e., .60 to .74) [16,17], indicating good test-retest reliability or stability over the 3-month period. Coefficients for Condition Management and Family Life/Leisure were lower, indicating fair test-retest reliability (i.e., .40 – .59) [16, 17]. Lower correlations might be expected because the parents' experience with the seizure condition was relatively new and therefore more likely to still be evolving. In other words, ratings at 3 and 6 months on items in these two subscales were less stable than the ratings on

the items in the other three subscales across the two time points. Intraclass correlation coefficients for the asthma sample were: Child Support (.52), Family Life Leisure (.54), Condition Management Confidence (.56), Autonomy (.67), and Discipline (.57). The Autonomy factor was in the “good” range and the other four factors were in the fair range indicating moderate stability in ratings over the 3-month period.

Validity—To evaluate the construct validity of the factors, relationships were explored between the five PRCI factors and related constructs at 6 months. It was hypothesized that all five of the PRCI factors would have a positive association with positive parent mood related to having a child with a seizure condition and to family mastery. In addition, we hypothesized specific relationships between each factor and other variables that, if found, would provide empirical support for validity. Specifically, we hypothesized that: (a) higher scores on Family Life/Leisure would be associated with lower scores on stigma; (b) higher scores on Condition Management would be associated with lower scores on need for information about the seizure condition; (c) higher scores on Child Autonomy would be associated with lower scores on parent worry; and (d) higher scores on Child Discipline would be associated with lower scores on child behavior problems. To test these hypotheses, relevant data were collected from the administration of six additional instruments: Parent Mood Scale, Family Inventory of Resources for Management [18], Parent Psychosocial Care Needs [19], Child Behavior Checklist [20], and Parent Stigma Scale [21]. Six month data were used because complete data were available for all related construct instruments. Descriptions of instruments follow.

Parent Mood: The Parent Mood Scale, which was developed for the study by the authors, asks parents to respond to pairs of adjectives that reflect parent affect or feelings associated with having a child with a health condition. For the measurement, parents were asked to think about how they felt being a parent of a child with a seizure condition and to respond with the extent to which they experienced each of following eight feelings: sad/gloomy, calm/relaxed, tense/fearful, angry/irritated, guilty/blamed, frustrated/exasperated, worried/nervous, and tired/spent 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 of the eight items was derived. A higher score reflects a more positive mood associated with the seizure condition. The internal consistency reliability was .87.

Family Environment: The Family Mastery subscale from the Family Inventory of Resources for Management (FIRM) [18] was used to measure the family environment. On this scale parents respond to items that describe the family environment on 4-point scales of 0 (*Not at All*) to 3 (*Very Well*) on items. A higher score reflects a more adaptive family environment. Items on the Mastery subscale reflect family emotion, sense of control over events, level of cooperation among family members, and family organization. The internal consistency reliability was .91.

Child Behavior Problems: The parents completed the Child Behavior Checklist (CBCL) [20] to measure behavior problems. The CBCL is a 118-item scale in which the children’s behavior problems during the past 6 months are rated using 3-point scales of 0 (*not true*), 1 (*somewhat or sometimes true*), and 2 (*very true or often true*). The reliability and validity of the CBCL as well as norms based on age and gender have been well established in past research [20]. The score used to test validity in this study was the Total Behavior Problems score.

Parent Perception of Stigma: The Parent Stigma Scale [22] was used to measure perceptions of stigma related to the child’s seizure condition. This 5-item scale asks parents to respond to items related to their perceptions of how others view their child’s seizure condition. Parents were asked to respond to items using 5-point Likert scales of 1 (*strongly disagree*), 2 (*disagree*),

3 (*neither*), 4 (*agree*), and 5 (*strongly agree*). A score is derived by summing the scores from the five items and deriving a mean score. A higher score reflects more perceived stigma associated with the child's seizure condition. The coefficient alpha for this scale was .77.

Parent Worry: Parent worry was measured using a subscale from the Parent Report of Psychosocial Care [19]. The Parent Worry subscale has five items related to parents' concerns and worries about their child's seizure condition such as possible causes (e.g., brain tumor) and possible negative effects of their child's seizures (e.g., brain damage). Parents were asked to rate how concerned or fearful they were on 4-point scales: 1 (*not at all*), 2 (*somewhat*), 3 (*moderately*), and 4 (*very much*). For scoring, the items were summed and divided by the number of items to obtain a mean score; a higher score reflects more parent worry. The internal consistency reliability was .84.

Parent Need for Information: A second subscale on The Parent Report of Psychosocial Care Scale [19] was used to measure parent need for information about the child's seizure condition. The Parent Need for Information subscale has 6 items that measure the extent of need for information related to the child's seizure condition, treatment, cause of seizures, how to handle future seizures, and preventing injury. Parents responded on scales from 1 (*no need for information or help*) to 3 (*strong need for information or help*). Items are scored and a mean score was used. A higher score reflects greater need. The coefficient alpha was .92.

Data Analyses and Results for Validity Testing—Pearson correlations were carried out to test proposed relationships among mean scores for each of the five PRCI factors and related constructs. Support for validity was found when the proposed relationships were in the direction predicted and key relationships were statistically significant. For completeness we have provided all of the correlation coefficients among the total scores for the factors and related constructs in Table 2 and Table 3.

Seizure Sample

Child Support—As hypothesized, parent provision of emotional support to the child was strongly associated with positive parent mood ($r = .31$) and family mastery ($r = .37$). These findings indicate that parents are better able to be emotionally supportive of the child in a family environment that is more adaptive and when the parent has positive perceptions related to having a child with a seizure condition. It would be anticipated that parents who live in families in which there is a sense of control over events and the level of cooperation among family members is high would be better able to provide emotional support to their child and have more time to help their child deal with the health condition.

Family Life/Leisure—Items on this subscale were designed to reflect impact of the child's health condition on the activities of the family with higher scores showing less negative impact. It was anticipated that the total score would be correlated with perceived stigma because parents might restrict leisure activities to reduce others from knowing about their child's health condition. We anticipated that parents who perceived more stigma associated with their child's seizure condition would restrict family activities more than families who perceived less. A negative correlation with parent perception of stigma ($r = -.46$) was found. In addition, we anticipated that parents who had a more positive affect associated with the child's health condition would be less likely to reduce family leisure activities. A positive correlation ($r = .37$) was found between the Family Life/Leisure subscale and parent positive mood associated with the child's seizure disorder.

Condition Management—Items on this subscale were designed to measure the parents' confidence in their ability to handle their child's health condition. It was predicted that parents

who reported fewer needs for information about their child's condition would have higher scores on condition management. As predicted, condition management was negatively associated with parent need for information about the seizure condition ($r = -.29$). Other anticipated relationships were also found. Condition management was positively related to positive parent mood associated with the seizure condition ($r = .30$) and family mastery ($r = .28$).

Child Autonomy—We anticipated that parents who encouraged greater autonomy in their child would have fewer worries about their child's health condition and also have a positive mood associated with having a child with a seizure condition. The strongest correlations were with parent positive mood ($r = .26$) and parent worry ($r = -.33$). Although we had hypothesized that parents would be more supportive of a child's autonomy in a better functioning family, the association was lower than expected ($r = .14$).

Child Discipline—For this final factor we hypothesized that parents of children with more behavior problems would have less confidence in their ability to manage their child's behavior. The correlation with child behavior problems ($r = -.55$) showed strong support for the validity of this factor.

New-onset Asthma Sample

To explore validity for the asthma sample we explored associations between concepts that were previously described for the seizure sample. With few exceptions, empirical support was found for hypothesized relationships (see Table 3). All of the factors had positive associations with parent positive mood. Although associations between each of the factors and family mastery were positive as anticipated, only those for Family Life/Leisure and Discipline factors were statistically significant. Other associations included Family Life/Leisure being positively associated with family mastery (.40) and negatively associated with stigma ($r = -.49$). Condition Management was negatively associated with parent worry ($r = -.26$) and need for information ($r = -.22$). Child Autonomy was positively associated with parent positive mood ($r = .39$) and negatively associated with child behavior problems ($r = -.28$). Finally, Child Discipline was negatively associated with child behavior problems ($r = -.35$).

Chronic Epilepsy Sample

In addition to the two samples described above we administered the scale to parents of a sample of children with chronic epilepsy. The sample is briefly described below and findings related to the psychometric properties found with this sample are reported. Subjects were 173 parents of children (85 girls and 88 boys) ages 9 to 14 years who at entry had had a definite diagnosis of epilepsy and had been receiving treatment for at least 6 months (mean length = 5.2 years). The majority of children (69%) had had a seizure in the past year. The mean child age was 11.4 years ($SD = 1.8$). The racial distribution for the children was: Caucasian (91%), African-American (6%), and other (3%). On average, the parent had greater than a high school education (Mean = 13.5 years, $SD = 2.3$). With few exceptions, the major caregiver was the mother. In this study we used the PRCI with a sample of families who had had longer experience with having a child with the health condition and also with helping their child in coping with the condition. In addition, the children in the sample were older in age.

The scale was administered three times: baseline, 12 months, and 24 months. Internal consistency reliabilities reported are from the baseline data collection as follows: Child Support (.71), Family Life Leisure (.89), Condition Management (.72), Child Autonomy (.60), and Child Discipline (.71). With the exception of Child Autonomy, the factors had reliabilities greater than .70. In addition, empirical support was found for hypothesized relationships between factors and related constructs. Child Support was positively associated with parent

mood ($r = .19$) and family mastery ($r = .21$). Family Life/Leisure was positively associated with parent mood ($r = .49$) and negatively associated with perceptions of stigma ($r = -.51$). Condition Management was positively associated with parent positive mood ($r = .30$) and parent need for information ($r = .45$). Child Autonomy was positively associated with parent positive mood ($r = .36$) and negatively associated with parent worry ($r = -.37$) about having a child with the condition. Finally, Child Discipline was positively associated with parent mood ($r = .36$) and child behavior problems ($r = -.51$).

Discussion

Empirical support for PRCI reliability and validity was found in two samples of parents of children with a new onset condition (seizures or asthma) and in one sample of children who had epilepsy. Children in the new onset seizure and asthma samples were relatively young (i.e., ages 4 to 14 years) and their parents had only a few months of experience with their child's condition; in some cases the diagnosis was not definite. Children in the epilepsy sample were older (i.e., ages 9 to 14 years) and on average their parents had over five years of experience with epilepsy. In all three samples parents were relatively well educated with mean years of education over 13 years.

Internal consistency reliabilities were consistently high for Family Life/Leisure, Condition Management, and Child Support subscales and adequate for the Child Autonomy subscale regardless of whether the children had new onset seizures or asthma or chronic epilepsy. Internal consistency reliabilities for the Child Discipline subscale were better for both of the seizure samples than for the asthma sample. Although empirical support for validity based on predicted correlations between subscale scores and related constructs was found for all three samples, findings varied across the three samples. For example, the correlation between Child Discipline and behavior problems was lower for the asthma sample than the two seizure samples. This weaker correlation for the asthma sample as well as the lower internal consistency reliability in Child Discipline in the asthma sample suggest that the items in the Child Discipline subscale do not measure the same general construct in the asthma sample as well as in the two seizure samples.

Additional empirical support was found for the predictive validity of three of the subscales in a previous report from the larger longitudinal study, specifically, changes in three subscale scores over a 24-month period were associated with expected changes in child behavior problems during the same period. Over the 24-month period decreases in Child Discipline and Child Autonomy scores were significantly associated with subsequent increases in child behavior problems. In addition, a reduction in the Child Support score, indicating less parental emotional support to the child, was significantly associated with an increase in child anxiety, depression, and social withdrawal behaviors over the 24-month period [21].

Because the instrument is designed to measure areas of parent response to a child's illness and there is empirical support for parental responses measured on the PRCI are related to child outcomes, items in the subscales could help identify content for parent interventions. For example, the finding that decreasing scores on the Child Support subscale were predictive of increases in child depression symptoms might suggest an intervention that provided parents with strategies for providing emotional support to their children with a new onset condition such as seizures. The PRCI could be used to measure parent perceptions of their emotional support to their child before and after the intervention.

The PRCI might also be useful as an assessment tool in a clinical setting, which might also suggest interventions in the clinical setting. For example, if parents have a low score on the Condition Management subscale, examining ratings of specific items could identify areas in

which parents need to receive information related to handling their child's health condition. In addition, the relatively high correlations between the Child Discipline subscale and the total behavior problem score on the Child Behavior Checklist in the seizure samples suggest that a low score on the Child Discipline subscale would warrant further assessment of child behavior problems. Clinical use, while promising, requires further testing of the scale. Use of such an instrument would be an important part of care of both the child with epilepsy and their parents and would expand the focus of care beyond seizure counts to quality of life.

Preliminary testing of the psychometric properties of the scale provided initial support for the reliability and validity of the PRCI. The instrument does have limitations, however. The tests of stability (test-retest reliability) in this report utilized a time period longer than the traditional period of time of two weeks to one month [24]. Moreover, the time period of measurement in this study might be a dynamic period in relation to understanding and acceptance of the disorder. Therefore, the findings might reflect adjustment to the disorder and not actual stability and the scores reported here may be underestimating test-retest reliability. Test-retest using a shorter time period will need to be established in future studies. Another limitation is the relatively high item scores on the Child Support and Family/Life Leisure factors. The high item means on these two subscales reflect a ceiling effect, which might be problematic if these subscales were used to test the effects of an intervention.

Although scale items were initially developed to reflect responses in parents of children with either seizures or asthma, the PRCI was also designed so that it could be adapted for use with parents whose children had other health conditions. To date it has been used with two samples of children with recent-onset conditions (epilepsy and asthma) and one sample of children with chronic epilepsy. We found that most of the psychometric properties were adequate when the PRCI was administered to parents of children with chronic epilepsy. The PRCI also may lend itself to other acute and chronic conditions as well. Further testing of the PRCI with new populations would be needed.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

1. Austin JK, Oruche UM, Dunn DW, Levstek DA. New-onset childhood seizures: parents' concerns and needs. *Clin Nurs Pract Epilepsy* 1995;2:8–10. [PubMed: 7850119]
2. Buelow JM, McNelis A, Shore CP, Austin JK. Stressors of parents of children with epilepsy and intellectual disability. *J Neurosci Nurs* 2006;38:147–154. 176. [PubMed: 16817666]
3. Rodenburg R, Marie Meijer A, Dekovic M, Aldenkamp AP. Family predictors of psychopathology in children with epilepsy. *Epilepsia* 2006;47:601–614. [PubMed: 16529629]
4. Austin JK, Caplan R. Behavioral and psychiatric comorbidities in pediatric epilepsy: toward an integrative model. *Epilepsia* 2007;48:1639–1651. [PubMed: 17565593]
5. Rutter, M.; Graham, P.; Yule, W. A neuropsychiatric study in childhood. London: S.I.M.P./William Heinemann Medical Books Ltd; 1970.
6. Davies S, Heyman I, Goodman R. A population survey of mental health problems in children with epilepsy. *Dev Med Child Neurol* 2003;45:292–295. [PubMed: 12729141]

7. Rodenburg R, Stams GJ, Meijer AM, Aldenkamp AP, Dekovic M. Psychopathology in children with epilepsy: a meta-analysis. *J Pediatr Psychol* 2005;30:453–468. [PubMed: 16055484]
8. Austin JK, Harezlak J, Dunn DW, Huster GA, Rose DF, Ambrosius WT. Behavior problems in children before first recognized seizures. *Pediatrics* 2001;107:115–122. [PubMed: 11134444]
9. Carlton-Ford S, Miller R, Nealeigh N, Sanchez N. The effects of perceived stigma and psychological over-control on the behavioural problems of children with epilepsy. *Seizure* 1997;6:383–391. [PubMed: 9663802]
10. Hoare P, Kerley S. Psychosocial adjustment of children with chronic epilepsy and their families. *Dev Med Child Neurol* 1991;33:201–215. [PubMed: 2026278]
11. Mitchell WG. Social outcome of childhood epilepsy: associations and mechanisms. *Semin Pediatr Neurol* 1994;1:136–143. [PubMed: 9422231]
12. Pianta RC, Lothman DJ. Predicting behavior problems in children with epilepsy: child factors, disease factors, family stress, and child-mother interaction. *Child Dev* 1994;65:1415–1428. [PubMed: 7982359]
13. Hodes M, Garralda ME, Rose G, Schwartz R. Maternal expressed emotion and adjustment in children with epilepsy. *J Child Psychol Psychiatry* 1999;40:1083–1093. [PubMed: 10576538]
14. Ostrom KJ, Schouten A, Kruitwagen CL, Peters AC, Jennekens-Schinkel A. Epilepsy-related ambiguity in rating the child behavior checklist and the teacher's report form. *Epileptic Disord* 2001;3:39–45. [PubMed: 11313222]
15. Chapieski L, Brewer V, Evankovich K, Culhane-Shelburne K, Zelman K, Alexander A. Adaptive functioning in children with seizures: impact of maternal anxiety about epilepsy. *Epilepsy Behav* 2005;7:246–252. [PubMed: 15996525]
16. Cicchetti DV, Sparrow SA. Developing criteria for establishing interrater reliability of specific items: applications to assessment of adaptive behavior. *Am J Ment Defic* 1981;86:127–137. [PubMed: 7315877]
17. Fleiss, JL. Statistical methods for rates and proportions. Vol. 2nd ed. New York: Wiley; 1981.
18. McCubbin, HI.; Thompson, AI. Family Stress Coping and Health Project. University of Wisconsin-Madison; 1991. Family assessment inventories for research and practice.
19. Austin JK, Dunn DW, Huster GA, Rose DF. Development of scales to measure psychosocial care needs of children with seizures and their parents. *J Neurosci Nurs* 1998;30:169–174. [PubMed: 9689608]
20. Achenbach, T.; Rescorla, L. Manual for the ASEBA school age forms & profiles. Burlington, VT: University of Vermont Research Center for Children, Youth, & Families; 2001.
21. Austin JK, Dunn DW, Johnson CS, Perkins SM. Behavioral issues involving children and adolescents with epilepsy and the impact of their families: recent research data. *Epilepsy Behav* 2004;5:S33–S41. [PubMed: 15351344]
22. Austin JK, MacLeod J, Dunn DW, Shen J, Perkins SM. Measuring stigma in children with epilepsy and their parents: instrument development and testing. *Epilepsy Behav* 2004;5:472–482. [PubMed: 15256183]
23. Rodenbur R, Meijer AM, Dekovic M, Aldenkamp AP. Family factors and psychopathology in children with epilepsy: a literature review. *Epilepsy Behav* 2005;6:488–503. [PubMed: 15907744]
24. Carmines, E.; Zeller, R. Reliability and validity assessment. Newbury Park, California: SAGE; 1979.

Table 1

Factors for Parent Response to Child Illness (PRCI) Scale for New-onset Seizure and Asthma Samples at 3 months

Item	Mean (SD)	Factor Loading	Item-to-Total Correlation
Child Support ($\alpha = .75$)			
(<i>Child's name</i>) usually feels better after I talk over worries with him/her.	4.34 (.71)	.73	.44
I cheer up (<i>child's name</i>) when he/she is sad.	4.46 (.68)	.69	.47
I am proud of the accomplishments of (<i>child's name</i>).	4.76 (.50)	.63	.49
(<i>Child's name</i>) talks to me when he/she is afraid.	4.28 (.69)	.54	.51
I like* (<i>child's name</i>) better when he/she does not disturb me.	4.02 (.94)	.50	.39
(<i>Child's name</i>) has his/her own feelings and ideas, and it is okay for him/her to tell me about them.	4.64 (.52)	.48	.46
I do a good job of supporting (<i>child's name</i>) in doing things that are hard for him/her.	4.19 (.71)	.37	.47
Despite best efforts, I am uncomfortable with how (<i>child's name</i>) and I get along.*	4.26 (.93)	.32	.46
Family Life/Leisure ($\alpha = .87$)			
We have fewer leisure outings with other families since (<i>child's name</i>) developed the (<i>health condition</i>).*	4.40 (.64)	.82	.76
My partner and I disagree about how to handle the (<i>health condition</i>).*	4.29 (.80)	.68	.61
Our family goes on fewer leisure outings because of (<i>child's name</i>)'s (<i>health condition</i>).*	4.26 (.74)	.65	.63
My partner and I differ about how to tell others about (<i>child's name</i>)'s (<i>health condition</i>).*	4.22 (.89)	.65	.57
My partner and I disagree about how to discipline (<i>child's name</i>) because of the (<i>health condition</i>).*	4.24 (.76)	.63	.62
I am often too tired from dealing with the seizure condition to do the things for fun that I used to do.*	4.36 (.72)	.60	.63
Having one child with a (<i>health condition</i>)* makes it difficult on other children in the family.	3.95 (.95)	.56	.52
I limit the activities of* (<i>child's name</i>) more than our doctor recommends.	4.21 (.84)	.52	.56
Our family activities outside the home are limited because of worry that (<i>child's name</i>) will have a (<i>health symptom</i>)* in front of others.	4.44 (.75)	.50	.54
My partner and I have less time to spend together because of (<i>child's name</i>)'s (<i>health condition</i>).*	4.28 (.72)	.41	.48
Condition Management ($\alpha = .77$)			
I feel confident in my ability to handle (<i>child's name</i>)'s (<i>health condition</i>).	4.00 (.84)	.76	.63
I know when to take (<i>child's name</i>) to the emergency room for the (<i>health condition</i>).	4.22 (.66)	.64	.61
I know what to do when the next (<i>illness symptom</i>) happens.	4.06 (.85)	.62	.48
I know how to recognize side effects or problems from (<i>child's name</i>)'s medicine for (<i>health condition</i>).	3.75 (.91)	.59	.45
I know when to call the doctor about (<i>child's name</i>)'s (<i>health condition</i>).	4.19 (.72)	.56	.52
When I think of myself as a parent of (<i>child's name</i>), I believe I can handle anything that happens.	4.02 (.85)	.52	.46

Item	Mean (SD)	Factor Loading	Item-to-Total Correlation
Child Autonomy ($\alpha = .64$)			
(Child's name) is my life's only focus.*	3.87 (1.07)	.66	.52
(Child's name) is overly dependent on me.*	3.32 (1.18)	.57	.40
I enjoy staying home with (child's name) more than going out with my friends.	2.32 (1.15)	.50	.33
I need to know what (child's name) is doing at all times.*	2.56 (1.23)	.46	.38
I give more attention to (child's name) than others in the family.*	2.96 (1.27)	.45	.35
The only time I am happy is when (child's name) is doing well	3.64 (1.11)	.37	.27
Child Discipline ($\alpha = .67$)			
Handling the behavior of (child's name) is hard for me.*	3.64 (1.13)	.68	.50
I find myself getting irritable with (child's name).*	2.79 (1.10)	.54	.41
I do a good job of disciplining (child's name).	3.84 (.83)	.48	.40
I usually understand what (child's name) needs from me.	4.03 (.77)	.39	.40
I am usually successful when I try to get (child's name) to do something.	3.73 (.91)	.35	.46

* **Scoring:** Items with an asterisk (*) are reversed for coding. Each item is assigned a score as follows: Strongly Disagree=1, Disagree=2, Not Sure=3, Agree=4, Strongly Agree=5. Scores for each subscale are summed and divided by the number of items to obtain a mean score. The instrument was not designed to have a total score.

Table 2
Correlations between PRCI subscales and related constructs for new-onset seizure sample at 6 months

Factors	Parent Positive Mood	Family Mastery	Parent Worry	Parent Information Needs	Parent Stigma	Child Behavior Problems
Child Support	.31⁺⁺	.37⁺⁺	-.08	-.07	-.26⁺⁺	-.23⁺⁺
Family Life/Leisure	.37⁺⁺	.20⁺⁺	-.21⁺⁺	-.22⁺⁺	-.46⁺⁺	-.24⁺⁺
Condition Management	.30⁺⁺	.28⁺⁺	-.09	-.29⁺⁺	-.25⁺⁺	-.10
Child Autonomy	.26⁺⁺	.14⁺	-.33⁺⁺	-.09	-.07	-.25⁺⁺
Child Discipline	.46⁺⁺	.50⁺⁺	-.22⁺⁺	-.15	-.24⁺⁺	-.55⁺⁺

Note: Coefficients in bold are those that were predicted to be associated in the direction found.

⁺ $p < 0.05$
⁺⁺ $p < 0.01$

Table 3
Correlations between PRCI subscales and related constructs for new-onset asthma sample at 6 months

Factors	Parent Positive Mood	Family Mastery	Parent Worry	Parent Information Needs	Parent Stigma	Child Behavior Problems
Child Support	.25 ⁺	.13	-.01	.14	-.07	-.20
Family Life/Leisure	.47 ⁺⁺	.40 ⁺⁺	-.35 ⁺⁺	-.14	-.49 ⁺⁺	-.17
Condition Management	.29 ⁺⁺	.16	-.26 ⁺	-.22 ⁺	-.41 ⁺⁺	-.00
Child Autonomy	.39 ⁺⁺	.20	-.17	.04	-.20	-.28 ⁺⁺
Child Discipline	.32 ⁺⁺	.43 ⁺⁺	-.17	-.02	-.34 ⁺⁺	-.35 ⁺⁺

Note: Coefficients in bold are those that were predicted to be associated in the direction found.

⁺ $p < 0.05$
⁺⁺ $p < 0.01$